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Maternal and adolescent illness beliefs about diabetes:
An exploratory study of its relationship to adolescent adherence, self-efficacy
and psychological well-being
& RESEARCH PORTFOLIO

PART ONE

(Part two bound separately)

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August 2007

Submitted in part fulfilment of the requirements for the
Degree of Doctorate of Clinical Psychology

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CHAPTER ONE
SMALL SCALE SERVICE RELATED PROJECT

Case Severity as measured by CORE outcome measure: Does it reflect case allocation
to Clinical Psychologists and Counsellors?

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Prepared in accordance to requirements for submission to Clinical Psychology
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Abstract

It is becoming increasingly common for Counsellors to be employed within Clinical Psychology Departments. With increased diversity in professions offering psychological therapies it is imperative to establish appropriate referral allocation systems, ensuring that referrals are seen by the most appropriate professional. The current study addressed this issue through a retrospective analysis of CORE outcome measure data obtained pre-therapy, to establish whether there were quantifiable psychometric differences between clients allocated to clinical psychologists and counsellors respectively. The study was conducted within a primary care psychology service and the data for 157 referrals were examined. This study found no quantifiable differences in CORE outcome scores for referrals allocated to clinical psychologists and counsellors. Possible explanations for the findings and recommendations for future research are outlined.

In recent years there has been a steady increase in the number of counsellors, and other professionals trained in psychological therapies, being employed within clinical psychology departments. According to Miller (1994) there are three main reasons for this: (1) the shortage of clinical psychologists, (2) pressures relating to cost efficiency and (3) the professionalisation of counselling. A number of benefits have undoubtedly resulted from this innovative approach to service delivery, such as reduced waiting times and increased patient satisfaction (Miller, 1994). However, there has been a proliferation in the number of studies examining the differences in the types of clients being seen by the various professionals within clinical psychology departments (Claxton et al. 1997; Kemp et al. 1998; Shannon et al. 2001).

Research findings indicate that there are clear indications for the types of clients and problems suitable for counsellors within a psychology department. Such problems include mild to moderate mental health problems, problems associated with life crises and relationship problems (e.g. Parker et al. 1997). Indeed, Kemp et al. (1997) state that “there is a general consensus regarding the types of patient appropriate to be seen by a counsellor” (Kemp et al., 1997, p13). Studies have also addressed the appropriateness of referrals to clinical psychologists, and Burton et al. (1995) found that clinical psychologists see more clients with relationship problems and personality problems.

Despite the apparent agreement between clinicians regarding the appropriateness of type of patients referred to different professions within clinical psychology departments, implementation continues to be an area of considerable difficulty. To

ensure the quality of future services it is imperative that professionals work within their optimum role.

The Mobray report (Management Advisory Service, 1989) described three levels of skill required to provide different levels of psychological intervention:

- Level one: Basic skills in establishing and maintaining relationships, simple and often intuitive techniques of counselling and stress management.
- Level two: Undertaking circumscribed psychological activities e.g. behaviour modification, which may be defined by protocol.
- Level three: A thorough understanding of varied and complex psychological theories and the ability to apply these to new problems to generate interventions.

Level three skills are said to be unique to clinical and counselling psychologists, while other health professionals are trained to levels one and two. This “tiered” approach to service delivery should ensure that patients are seen by the most appropriate mental health professional. The “tiering of psychological services involves identifying and prioritising levels of psychological need and organising service provision accordingly” (Kellet and Newman, 2003, p27). At a departmental level the tiered approach to service delivery allows clients to be seen by the professional trained and able to address their problem. The tiered approach is also useful as it allows the structure and skill mix within departments to reflect the differing needs of the clients referred for psychological help. The MPAG report recommended that clinical psychologists should not undertake work that can be done equally well by other staff,

provided adequate support and supervision are available (MPAG, 1990). The effect of this being clinical psychologists have more time to devote to their increasing role in consultancy and supervision.

In September 2002, a clinical psychology department within the West of Scotland introduced CORE (Clinical Outcomes in Routine Evaluation) as a means of evaluating, auditing and measuring outcomes for psychological therapies. CORE comprises an “outcome measure” which is a measure of global distress and is completed at assessment or pre therapy and again at the end of therapy. This is a self-rated measure and comprises 4 dimensions (1) well-being, (2) problems/symptoms, (3) life functioning, and (4) risk. It assesses how the client has felt over the previous week on the basis of responses to 34 self-statement items, using a Likert scale from 0 – ‘not at all’ to 4 – ‘most of the time’. The measure has demonstrated satisfactory reliability, validity and sensitivity to change on the basis of a large multi-site study of clinical and non clinical data (Evans et al.2002; Barkham et al. 2001). Kemp et al. (1998) outlined the need for psychometric data to be used to investigate differences between clients allocated to professions; the introduction of CORE to this clinical psychology service makes such analysis possible.

The team offering psychological therapies for adult mental health referrals comprised 7 clinical psychologists, 9 counsellors, 1 CBT therapist and 2 psychotherapists. The current study addressed only the first two groups, namely clinical psychologists and counsellors, as there was insufficient data available for the small number of other professionals offering psychological therapies. Currently, allocation of referrals in the department is by means of presenting problem as judged by referral letter. To

establish the effectiveness of this system of allocation, pre-therapy CORE outcome scores were compared retrospectively between referrals allocated to clinical psychologists and those allocated to counsellors. It was hypothesised that if the current referral system was functioning appropriately, reflecting a tiered approach to allocation, then higher CORE outcome scores would be expected in patients allocated to clinical psychologists, and lower scores for those allocated to counsellors.

Hypothesis

CORE outcome scores, which reflect severity of problem, would be expected to be higher for cases allocated to clinical psychologists, than those allocated to counsellors, reflecting a tiered approach to service delivery.

Methods

Design

The study retrospectively reviewed CORE outcome measure scores obtained pre-therapy. These data were then considered in the context of subsequent allocation of cases to clinical psychologists and counsellors offering psychological therapies within the clinical psychology department. These data were recorded and accessed via a CORE database within the clinical psychology department.

Data set

Data comprised all referrals and completed CORE outcome measures obtained between September 2002 and March 2003 (n=156). This retrospective sample included data from referrals allocated to clinical psychologists (n=87) and counsellors (n=69), but not those allocated to psychotherapists and CBT therapists due to the small number of referrals allocated to these professionals (n= 10).

Procedure

The CORE domain sub scores of (1) well-being, (2) problems or symptoms, (3) functioning, (4) risk, (5) total, (6) total (excluding risk) were analysed to ascertain whether cases allocated to clinical psychologists and counsellors differed. The CORE yields ordinal data. These data were not normally distributed and were therefore analysed using Mann Whitney tests. SPSS (version 9) was used for statistical analysis.

Results

Demographic data for patients allocated to clinical psychologists and counsellors are presented in Table 1.

*** Insert Table 1 ***

In terms of demographic data there were no significant differences in the age of clients allocated to profession ($t=.985$, $df153$, $p=.326$). It appeared that there were differences in respect of gender, with clinical psychologists being allocated more male clients as compared to counsellors, however, this was not significant (χ^2 , 37.9, $p=.609$).

The mean rank scores obtained from the pre-therapy CORE outcome measure are displayed for the two professional groups in figure 1 below.

*** Insert Figure 1 ***

Potential between group differences were examined using Mann Whitney tests. The results of these analyses are displayed in Table 2. No significant differences were found in respect of all domains.

*** Insert Table 2 ***

Discussion

The present study aimed to investigate the differences between clients allocated to clinical psychologists or counsellors within a team offering psychological therapies, on the basis of retrospective analysis of CORE outcome scores. These pre-therapy scores reflect the severity of referred problem, and were used to ascertain whether the current allocation system reflected a tiered approach to service delivery.

No significant differences were found in the domain scores of 'well-being', 'problems or symptoms', 'functioning', 'risk', 'total' or 'total excluding risk' between clients allocated to clinical psychologists and counsellors. Allocation of referrals is currently by referral letter. If we are to assume that clinical psychologists and counsellors are seeing different types of clients in keeping with BPS guidelines (BPS, 1994) then we may have expected differences in the severity of cases as measured by CORE.

However, the lack of statistically significant differences between these two groups has been demonstrated elsewhere by Kemp and Thwaites (1998), who used the SCL-90 in an attempt to establish such differences between clients allocated to clinical psychologists and counsellors.

There are a number of reasons that may explain the lack of observed significant differences. First of all, the null hypothesis may be true; there is no difference between patients allocated to clinical psychologists and counsellors in respect of severity as measured by CORE. Kemp & Thwaites (1998) forward an interesting hypothesis to explain the lack of differences in respect of psychometric data. They propose that clients of clinical psychologists are more likely to have experienced serious problems over long periods of time as compared to clients of counsellors. If the tiered approach to case allocation is operating effectively, then clients allocated to counsellors should have experienced more short-term, life event related problems. If this is the case then it may be that this latter group are more inclined to rate their subjective distress as higher than those with long-standing problems (Kemp & Thwaites, 1998).

A methodological issue related to the above is that CORE assesses subjective distress during the previous week. This may be reported as greater in those allocated to counsellors due to the differing nature of the problems they present with and the shorter duration of symptoms than those allocated to clinical psychologists. Although CORE has demonstrated satisfactory properties for assessing the effectiveness of psychological therapies at outcome (Evans et al. 2002), it may not be the most appropriate measure on which to base decisions regarding allocation.

A further explanation may be that clients are being wrongly allocated on the basis of information contained in the referral letter. However this aspect of allocation was not addressed by the current study.

In conclusion, although no significant differences were found between clients allocated to clinical psychologists and counsellors in respect of CORE data, the present study suggests that the use of CORE outcome data to assess the appropriateness of case allocation to different professions within the team is limited.

The question of case allocation to professionals within the team is an important one. Further research may benefit from the addition of an objective measure of case severity and chronicity. This would help to determine the nature of the lack of statistical differences in data obtained from referrals to clinical psychologists and counsellors. Inclusion of such a measure may help to ascertain whether there is a differential reporting of psychological distress between clients with shorter or longer duration of problems. Further research is required to establish whether referrals are allocated to the most appropriate professional within the team, thereby adhering to a tiered approach to service delivery.

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Table 1: Demographic characteristics of participants by profession allocated to

Profession	<i>n</i> (ΣN=157)	Mean Age in years (SD)	Gender (per cent)	
			Male	Female
Counsellor	69	39.87 (12.46)	20	80
Clinical Psychologist	87	37.98 (11.38)	41	59

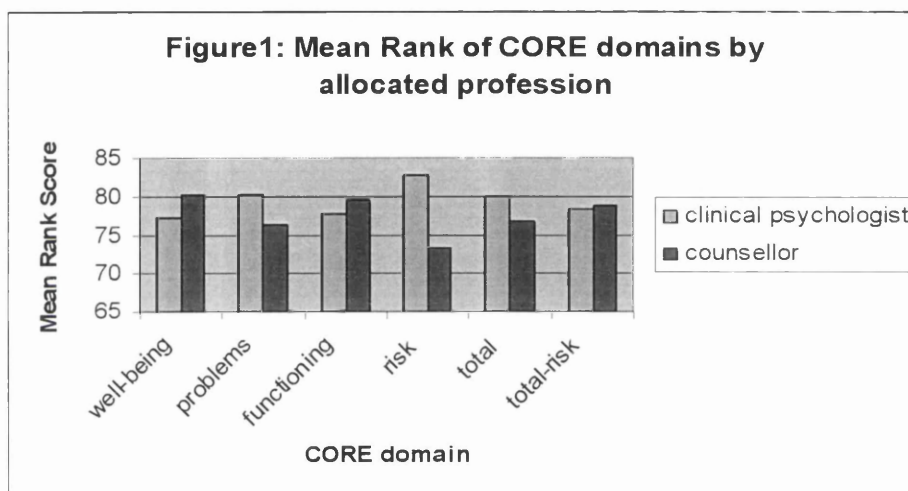


Table 2: Mann Whitney tests of CORE data of clients allocated to Clinical Psychologists and Counsellors

		Well-being	Problems	Functioning	Risk	Total	Total excluding risk
Mean Rank (1)		77.18	80.22	77.74	82.61	79.84	78.29
Mean Rank (2)		80.17	76.33	79.46	73.32	76.81	78.76
Sig. (2 tailed) 95% Confidence Intervals	upper	.668	.593	.807	.190	.681	.944
	lower	-.686	-.612	-.822	-.206	-.699	-.953

(1) – clinical psychologist (2) – counsellor

CHAPTER 2

SYSTEMATIC REVIEW

Systematic review of the illness beliefs of adolescents with Type 1 diabetes.

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Psychology (Appendix 2.1)

Abstract

Background: Type 1 diabetes is a chronic illness which is often diagnosed during childhood and adolescence. The aim of treatment is to control blood glucose levels and by doing so avoid serious complications, as such, adherence to treatment regimes is of great importance. The Self-Regulatory Model (SRM) provides a framework to evaluate individuals' beliefs about their illness and how these relate to health outcomes.

Aims: The study aims to review the literature for studies exploring illness beliefs of adolescents with Type 1 diabetes and their relationship to demographics, adherence, psychological well-being, self-efficacy and social factors.

Method: Published articles between 1985 and 2007 concerning adolescent illness beliefs and Type 1 diabetes were identified using a systematic search strategy.

Results: Eight articles met the inclusion criteria. Four out of six studies reported a significant relationship between illness beliefs and demographic variables. With regard to physiological adherence only one study supported the SRM and found a relationship between illness beliefs and physiological adherence. There was more consistency between studies reporting relationships between illness beliefs and self-reported adherence and psychological morbidity/well-being. One study addressed self-efficacy beliefs and reported significant relationships with illness beliefs. Social factors and their relationship to illness beliefs were addressed by three studies; two studies reported significant relationships between illness beliefs and social support and one study reported significant differences between the illness beliefs of mother and child.

Conclusion: The SRM has provided some valuable insights into adolescent illness beliefs in Type 1 diabetes. Further research in this area is needed to confirm the existence of relationships between illness beliefs and health outcomes and in doing so this could have important implications for future clinical interventions with this vulnerable group.

Introduction

Type 1 diabetes is a chronic medical condition characterised by elevated blood glucose levels due to autoimmune destruction of the insulin producing cells in the pancreas. It is often diagnosed in childhood or adolescence and while the exact cause is unknown, immunological and genetic factors have been implicated. At an individual level the child or adolescent with diabetes must adhere as closely as possible to a complex and multicomponent treatment regime to avoid the serious and life threatening complications of Type 1 diabetes. Short-term complications, namely hypoglycaemia and diabetic keto-acidosis (DKA), relate to acute changes in blood glucose concentration and can be life threatening. Longer term complications usually develop after more than 15 years of diabetes and are a major cause of morbidity and mortality. These complications include retinopathy, nephropathy, neuropathy, heart disease, peripheral vascular disease and stroke and are positively correlated with measures of blood glucose levels.

To reduce the chances of developing these complications the individual with Type 1 diabetes must learn to carefully monitor and regulate their own blood glucose. This requires frequent monitoring of blood glucose levels (approximately four times per day), regular injections of insulin (at least twice daily), adherence to a carbohydrate controlled, healthy eating diet and regular exercise. Regular attendance at diabetes out-patient clinics is essential to monitor treatment effectiveness, measure glycaemic control, assess and manage short term complications and screen for and prevent longer term complications. Glycated haemoglobin (HbA1c) provides a measure of mean glycaemic control over the preceding three months. High HbA1c levels indicate poor glycaemic control.

In addition to the challenges of managing their diabetes, adolescents with diabetes must navigate their way through the normal changes and stages of adolescence including the physiological, psychological, emotional, cognitive and social developments specific to this stage of development. It is no surprise that glycaemic control is often poor during adolescence. This has been partially attributed to physiological changes during adolescence however, a reduction in adherence behaviours to the treatment regime have been implicated as a major cause (Jacobson et al., 1987). The landmark Diabetes Control and Complications Trial (DCCT, 1994) demonstrated that good glycaemic control can dramatically reduce long term complications in later life and therefore it is of paramount importance to establish ways to help this group of young people achieve optimal glycaemic control throughout their adolescent development.

The self-regulatory model (SRM)

Within health psychology there has been a proliferation of research to explore the psychological and cognitive factors related to the experience of chronic illness. To this end, a number of models and theories have emerged which attempt to encapsulate how people think about their illness and how this then impacts on outcomes such as adherence to treatment. One such model is the Self-Regulatory Model (SRM) proposed by Leventhal and colleagues. This model is also referred to as the 'common-sense model of self-regulation of health and illness' or the Common Sense Model (CSM). The model postulates that people construct their own personal common-sense model of their illness in order to understand and respond to the difficulties it presents (Leventhal et al.1980; Leventhal et al.1992; Leventhal & Benyamini, 1997). It is proposed that beliefs about the illness are formed around five broad cognitive

dimensions: illness identity which concerns the symptoms associated with the illness; timeline which refers to the chronicity of the illness or its tendency to recur; cause, that is causal attributions of the disease; consequences of having the illness, for example the daily impact of the disease; and lastly personal and treatment control, that is the perceived level of personal control over the illness and beliefs about the effectiveness of treatment to cure or control the illness. The dimensions of the SRM have been operationalised in the Illness Perception Questionnaire (IPQ) (Weinman et al. 1996), recently revised as the Illness Perception Questionnaire - Revised (MossMorris et al., 2002). Two additional dimensions were added to the five original dimensions; emotional representations, the person's emotional response to their illness, and an illness coherence dimension which refers to the person's understanding of the illness. Patient held beliefs in these domains are proposed to relate to coping behaviours including adherence to treatment regimens, and health outcomes in people experiencing ill health. The SRM is described as a dynamic system, and appraisal of coping effectiveness informs cognitive and emotional representations of the illness and future coping responses.

The SRM has been applied to a variety of chronic illnesses including coronary heart disease (Byrne et al. 2005), Chronic Fatigue Syndrome and Addison's disease (Heijmans & de Ridder, 1998), epilepsy (Kemp et al.1999), hypertension (Ross et al. 2004) and diabetes (Hampson et al. 1995).

A recent meta-analysis of forty five studies using the SRM indicated that there was a reliable empirical basis for the proposed relationship between illness beliefs, coping and outcomes (Hagger & Orbell, 2003). This meta-analysis addressed the

relationships between the 5 dimensions identity, timeline, consequences, causal factors and control/curability of illness and concluded that a chronic timeline, more serious consequences, a strong illness identity and a high number of symptoms were associated with poorer adjustment and outcomes, whereas a higher perceived level of controllability/curability was associated with better adjustment. The SRM has been used to explore adherence to treatment in diverse chronic illness populations and there is strong evidence that the dimensions are stable across illnesses. However, Hagger and Orbell (2003) highlighted that the pattern of beliefs varies across illnesses and ought to be explored for different illness groups. A further review by Petrie et al. (2007) reported that studies to date have explored the relationship between illness perceptions and their relationship to important health outcomes across a variety of illnesses.

With regard to the literature concerning adults with diabetes, the SRM has been employed to explore relationships between illness beliefs and adherence (Patino et al. 2005; Wooldridge et al. 1992), care-seeking behaviour (Lawson et al. 2004) and self-management (Glasgow et al. 1997). Although a number of studies have been conducted in this area there has been no diabetes specific systematic review of the literature as reviews have reported on illness perceptions across a broad range of acute and chronic illnesses (Hagger & Orbell, 2003).

In addition to the application of the SRM to adult patients with diabetes, the SRM has been applied to adolescents with Type 1 diabetes. The SRM has been used to explore relationships between illness beliefs and metabolic control (Brownlee-Duffeck et al., 1987), quality of life (Copp et al. 1998), emotional well-being (Edgar & Skinner,

2003) self-efficacy (Griva, et al. 2000) and self-care (Skinner & Hampson, 1998). There has to date been no systematic review of the literature concerning the illness beliefs of adolescents with Type 1 diabetes and how these relate to health outcomes. To this end the current study aims to systematically search and evaluate the literature to address the following aims:

Aims

1. What are the illness representations of the adolescent with Type 1 diabetes and how do they relate to demographic variables such as gender and age?
2. Are illness representations associated with measures of
 - glycaemic control
 - self-care
 - self-efficacy
 - and psychological well-being /psychological morbidity?
3. What is the relationship between social factors, illness representations and these outcomes?

Method

Selection process and data extraction

A systematic review of the literature was conducted, and the databases Medline (Jan 1985 –May 2007), PsychINFO (Jan1985 – May 2007), the Cochrane Database (Jan 1985-May2007), and CINAHL (Jan 1985-May2007) were searched for relevant studies concerning adolescent illness beliefs about Type 1 diabetes, by combining ‘diabetes’ with the following search terms: ‘illness representation’, ‘illness perception’ ‘illness belief’, ‘personal models’, ‘self-regulatory’ and ‘Leventhal’. Key journals were electronically searched, including Diabetes Care and the British Journal

of Health Psychology. The reference section of each article meeting criteria was checked for additional sources. In addition, articles citing included studies were identified and explored. Studies were selected for entry according to the inclusion and exclusion criteria (see Table 1).

Assessment of study quality

Demographic, sampling, methodological and clinical data were extracted from each article and critically rated on a 29 item scale (see Appendix 2.2) based on SIGN 50 guidelines and modified for use with cross-sectional and longitudinal designs (www.sign.ac.uk). A score of 1 was awarded if the study met quality criteria and 0 if it did not. Each item was of equal weighting and total scores expressed as percentages. Studies were classified as of high >75%, moderate 60-75%, low 50-59% and poor quality < 49%. An independent reviewer rated half of the studies. Agreement was high (90%) and differences were resolved through discussion.

*** Insert Table 1 ***

Results

The electronic search revealed 102 studies of which 83 were discarded on title alone (see figure 1). The abstracts of the remaining 19 studies were assessed and 13 were excluded as they did not meet exclusion and inclusion criteria (see Table 2 for a summary of excluded studies).

*** Insert Figure 1 ***

The reference sections of the 6 included studies were searched and 2 further studies were identified. 8 studies were therefore included in the systematic review (Table 3) and rated as outlined in Appendix 2.2.

*** Insert Table 2 ***

Some of the studies use samples from the same pool of participants e.g. Law et al. (2002) used the same sample as Law (2002). In addition the longitudinal study by Skinner et al. (1998; 2000; 2001) reported findings at three time points. The paper included by Skinner et al. (2003) was comprised of a series of four studies, of which three met the inclusion criteria and are included. These studies are discussed as individual studies as they examined disparate aspects of illness beliefs and used different adolescent samples.

*** Insert Table 3 ***

Quality of studies

Included studies had a range of quality scores between 62-86% (see Appendix 2.2).

The quality criteria were divided into discrete areas reflecting key methodological issues (aims, sampling procedure, demographic details, clinical characteristics, measures of assessment, analysis and interpretation) which will be discussed in turn (see Appendix 2.2).

Aims

The aims and hypotheses were clearly stated in all of the included studies.

Sampling procedure

Sample size and origin was reported in all studies. Inclusion and exclusion criteria were clearly identified. Recruitment was mainly within out-patient departments with varying participation rates. In the majority of studies no data about non-participants was available and the authors were therefore unable to comment on sample representativeness. However, Griva et al. (2000) reported a high participation rate of 77%, reported data on non-participants and was able to demonstrate that the study sample was representative. The study by Skinner et al. (2003) to develop the Diabetes Illness Representations Questionnaire recruited its sample from the membership of Diabetes UK and reported a low response rate. Loss of subjects to follow up was relevant only to the longitudinal study (Skinner & Hampson, 1998; Skinner et al, 2000; Skinner & Hampson, 2001) and was adequately addressed.

Demographic details and clinical characteristics

Demographic details were included in all studies. Griva et al. (2000) included adolescent participants (15-19 years) and young adults (20-25 years). There were no significant differences on any of the independent or dependent measures used and the group was thereafter analysed as a whole. Clinical characteristics were observed across studies. All studies reported the mean and standard deviation for the duration of diabetes. Edgar & Skinner (2003) was the only study to include information about the age of the participant at diagnosis.

Most studies included information about the duration of the study, usually between 3-4 months thereby avoiding difficulties related to seasonal variation in glycaemic

control. The extended recruitment period from November to June reported by Law et al. (2002) could be a potential confounding variable for measures of glycaemic control.

Measures of assessment

All studies used a measure of illness beliefs based on the SRM (Leventhal et al. 1980). For details please see Table 3. For outcome variables all studies used measures which were reliable and validated such as HbA1c and the Summary of Diabetes Self-Care Activities (SDSCA); the Well-being questionnaire (WBQ) had not been validated with young adolescents and was modified for use with them.

Analysis and Interpretation

None of the studies included calculations of power or sample size. All statistical analysis seemed appropriate although Law (2002) used regression analysis with a small sample (n=30). A number of studies employed multiple comparisons and adjusted the significance level rather than performing a Bonferroni correction. The interpretation of the results was of a high standard and gave direction for future research. Some studies also offered suggestions for clinical practice.

Adolescent Illness beliefs and their relationship to demographic variables

Six studies reported on relationships between illness beliefs and demographic variables (Skinner & Hampson, 1998; Skinner et al., 2000; Skinner & Hampson, 2001; Skinner et al. 2003; Law et al. 2002; Griva et al. 2000). Four of these reported significant relationships between illness beliefs and demographic variables (Skinner & Hampson, 1998; Skinner et al., 2000; Skinner & Hampson, 2001; Skinner et al. 2003).

These studies consistently reported that female participants demonstrated stronger negative beliefs about the serious consequences of diabetes than male participants. In addition the fourth study reported in Skinner et al. (2003) reported that female participants were more likely to endorse statements that diabetes is of a permanent nature.

With regard to age, Skinner et al. (2003) found that older adolescents were more likely to report that diabetes is a chronic condition and to view their diabetes as permanent. In addition, older adolescents held significantly more positive beliefs about the effectiveness of their treatment regime to control their diabetes (Skinner et al. 2003). In contrast, no significant relationships were found between illness representations and demographic variables in two papers (Law et al. 2002; Griva et al. 2000). None of the studies reported a relationship between duration of diabetes and illness beliefs.

Summary

- Four studies found a significant relationship between gender and illness beliefs. Female participants viewed diabetes as having more serious consequences (Skinner & Hampson, 1998; Skinner et al., 2000; Skinner & Hampson, 2001) and endorsed beliefs about the chronic nature of diabetes more so than male participants (Skinner et al. 2003).
- One study reported a significant association between beliefs about the chronicity of diabetes and age (Skinner et al. 2003).
- Two out of the six studies reported no significant relationship between demographic variables and illness beliefs (Law et al. 2002; Griva et al. 2000).

- None of the studies found a relationship between illness beliefs and duration of diabetes.

Illness beliefs and associations with glycaemic control and physiological measures of adherence

Five out of the eight studies used HbA1c values as a measure of physiological adherence. (Griva et al. 2000; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002). Griva et al. (2000) was the only study to report significant associations between HbA1c and beliefs about the identity, consequences and control of diabetes, meaning that better glycaemic control i.e. lower HbA1c levels were significantly correlated with fewer reported symptoms, fewer consequences and stronger beliefs that diabetes can be controlled. In contrast, the remaining four studies found no direct association between illness beliefs and glycaemic control (Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002). However, Skinner & Hampson, (2001) did report that female gender and high anxiety levels were significant predictors of poor glycaemic control. This relationship was mediated by dietary self-care. This finding was partially replicated in the study by Law et al. (2002) which reported a similar relationship between glycaemic control and anxiety.

Summary

- One study reported associations between beliefs about control, identity and consequences of diabetes and physiological adherence as measured by HbA1c (Griva et al. 2000).

- The remaining four studies found no relationship between illness beliefs and physiological adherence as measured by HbA1c (Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002).
- Two studies reported a significant relationship between physiological adherence and anxiety; higher HbA1c associated with higher anxiety levels (Skinner & Hampson, 2001; Law et al. 2002).

Illness beliefs and associations with self-reported adherence

Six studies measured self-reported adherence to the treatment regimen and its relationship to illness beliefs (Griva et al. 2000; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002; Skinner et al. 2003). With the exception of Griva et al. (2000) all studies used the SDSCA (Toobert & Glasgow, 1994) to measure self-reported adherence. Griva et al. (2000) used a measure based upon the Beliefs about Medicines Questionnaire (Horne et al. 1999).

Five studies reported significant relationships between illness beliefs and self-reported adherence (Griva et al. 2000; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Skinner et al. 2003). The most consistent finding was that positive beliefs about control were significantly associated with better self-reported dietary adherence (Griva et al. 2000; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Skinner et al. 2003). In addition, Griva et al. (2000) reported that beliefs about control were related to self-reported adherence to insulin administration, blood glucose monitoring and exercise recommendations. Regression analysis showed that the only significant predictor from the IPQ was the perceived control subscale, accounting for 39% of the variance in self-reported adherence. Griva et al. (2000)

reported that dietary adherence was found to be negatively related to identity, indicating that identification of fewer symptoms related to diabetes was associated with improved dietary adherence. Skinner et al. (2000) reported significant intercorrelations between blood glucose monitoring, insulin administration and dietary self-care. Increased engagement in any one of these behaviours was associated with increased participation in the others. Further, this study reported that better dietary self-management was associated with a shorter duration of illness (Skinner et al., 2000). Law et al. (2002) reported no significant relationship between illness beliefs and self-reported adherence to the treatment regimen. They did report a significant relationship between adherence to the dietary and insulin administration components of the treatment regime to glycaemic control; more frequent engagement in these self-care behaviours being related to better glycaemic control.

Summary

- Five out of six studies reported associations between illness beliefs and self-care behaviours. Beliefs about control were associated with dietary self-care (Griva et al. 2000; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Skinner et al. 2003).
- Griva et al. (2000) found associations between beliefs about control and adherence behaviours for the insulin administration, blood glucose monitoring and exercise components of the diabetes treatment regime. Beliefs about control accounted for 39% of the variance in self-reported adherence.
- Fewer symptoms associated with diabetes were found to be associated with better dietary adherence (Griva et al. 2000).

- There was a great deal of consistency between studies, only one study reported no association between self-reported adherence and illness beliefs (Law et al. 2002).

Illness beliefs and associations with self-efficacy

Griva et al. (2000) was the only study to explore the relationship between illness beliefs and self-efficacy beliefs using the Self-efficacy for diabetes scale, covering general self-efficacy and diabetes specific self-efficacy. They reported that both general and diabetes specific self-efficacy beliefs were associated with the control subscale of the IPQ indicating that positive beliefs about the controllability of diabetes is related to higher levels of self-efficacy. In addition, positive beliefs about diabetes specific self-efficacy were associated with fewer diabetes associated symptoms (identity sub-scale) and less perceived consequence of diabetes (consequences sub-scale).

Summary

- Positive beliefs about control were found to be associated with higher levels of self-efficacy (Griva et al. 2000).
- Endorsement of fewer symptoms associated with diabetes was related to higher levels of diabetes specific self-efficacy (Griva et al. 2000).
- Beliefs endorsing less serious consequences of diabetes were associated with higher levels of diabetes specific self-efficacy (Griva et al. 2000).

Illness beliefs and associations with psychological well-being / psychological morbidity

Six studies measured psychological well-being (Edgar & Skinner, 2003; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002; Skinner et al. 2003) using the WBQ which is a diabetes specific measure of anxiety, depression and psychological well-being (Bradley, 1994). Three studies reported that negative beliefs about the consequence of having diabetes were associated with higher levels of anxiety and depression (Edgar & Skinner, 2003; Skinner & Hampson, 1998; Skinner et al. 2000). In addition, higher levels of anxiety were predicted by more negative beliefs about the impact of diabetes on day-to day functioning (Skinner & Hampson, 2001). Beliefs about the consequences of diabetes and beliefs about the identity of the illness were associated with depression, anxiety and positive well-being (Skinner et al. 2003). Positive well-being was also related to beliefs about control (Edgar & Skinner, 2003; Law et al. 2002). Finally, Law et al. (2002) reported that the consequences scale and the personal control scale of the IPQ-R were positive predictors for anxiety and positive well-being. Regression analysis revealed that using the total of all of the scales of the IPQ-R accounted for 52% of the variance in anxiety and 32% for positive well-being. However, it is questionable whether summing all dimensions of the IPQ-R is meaningful given the diversity of cognitive beliefs included; this technique was not used in any other studies under review. Furthermore this study had a small number of participants (n=30).

Summary

- All studies reported a relationship between illness beliefs and aspects of well-being. The most consistent finding was that beliefs about the consequences of diabetes were found to be related to anxiety, depression and positive well

being. (Edgar & Skinner, 2003; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002; Skinner et al. 2003).

- Anxiety was associated with beliefs about illness identity (Skinner et al. 2003).
- Positive beliefs about control were associated with higher levels of positive well-being (Edgar & Skinner, 2003; Law et al. 2002).
- One study reported that personal control predicted anxiety and positive well-being (Law et al. 2002).

Adolescent Illness beliefs and their relationship to social factors

Three studies addressed the relationship between illness beliefs and social factors (Skinner & Hampson, 1998; Skinner et al. 2000; Law, 2002). Skinner & Hampson (1998) investigated the role of social support in relation to illness beliefs, self-care and well-being. This study found that older age of participants was associated with self-reported lower levels of diabetes specific family support for dietary self-management. Female adolescent subjects reported higher levels of peer support than males. General family and friend support was related to dietary self-management and for diabetes specific support, family and friend support was related to blood glucose monitoring and diabetes specific family support was related to insulin administration. The relationship between beliefs about treatment effectiveness and dietary self-management was found to be partially mediated by family support, suggesting that supportive families may encourage positive beliefs about the effectiveness of the diabetes treatment regimen. The follow-up study (Skinner et al., 2000) concluded that support from friends and family were predictive of better dietary self-care and that this relationship was mediated by adolescents' beliefs about the effectiveness of treatment to control diabetes.

Law (2002) explored the social context of illness beliefs in a comparative study of adolescent and maternal beliefs about diabetes (Law, 2002). This study reported significant differences on two dimensions of the IPQ-R; maternal subjects believed that diabetes had more serious consequences and a greater emotional impact than their child did.

Summary

- Beliefs about treatment effectiveness were found to partially mediate the relationship between dietary self-care and social support from family and friends. Supportive families may encourage positive beliefs about the effectiveness of the treatment regime (Skinner & Hampson, 1998; Skinner et al.2000)
- Maternal and adolescent illness beliefs were reported as significantly different for beliefs about the consequences and emotional impact of diabetes (Law, 2002).

Discussion

1. What are the illness representations of the adolescent with Type 1 diabetes and how do they relate to demographic variables such as gender and age?

Four out of six studies reported that illness beliefs are associated with demographic variables such as age and gender. The longitudinal study reported by Skinner and colleagues (considered as discussed above as three studies) (Skinner & Hampson, 1998; Skinner et al., 2000; Skinner & Hampson, 2001) reported that female

participants endorsed more negative beliefs about the consequences of diabetes. In addition, a significant age effect was found in that older participants were more likely to endorse beliefs about the permanent and chronic nature of diabetes (Skinner et al., 2003). In contrast two studies, (Griva et al., 2000; Law et al., 2002) found no relationship between demographic variables and illness beliefs. These differences may be partially attributed to the wide age range referred to as 'adolescent' (11 to 19 years) as discussed below. Both the empirical literature and clinical practice supports the hypothesis that adolescents are gradually given more responsibility for their diabetes and one factor important to the transfer of power from care-giver to adolescent is age (Skinner et al. 1996).

None of the studies found a relationship between illness beliefs and duration of diabetes and only one study (Edgar & Skinner, 2003) included information about the age of the adolescent at diagnosis. Children who have had diabetes for many years may demonstrate different illness beliefs than those who are newly or recently diagnosed. One factor contributing to this is the 'honeymoon' period following diagnosis when glycaemic control is good due to some residual insulin production. Furthermore, at the point of diagnosis adolescents may have little information to draw on to construct illness beliefs. Exclusion of newly diagnosed subjects would eliminate these potential confounding variables.

Additionally, it is possible that children diagnosed at an earlier age may adjust differently to diabetes than children diagnosed later, during adolescence. However, none of the studies reported data pertaining to the age of the child/adolescent at

diagnosis. This may be an important variable in need of investigation and could account for some of the conflicting results.

2. Are illness representations associated with measures of

- **physiological adherence**
- **self-reported adherence**
- **self-efficacy**
- **and psychological well-being /psychological morbidity?**

Physiological adherence

Only one study out of five found significant associations between illness beliefs and physiological adherence, with lower HbA1c values associated with positive beliefs about control and the consequences of diabetes (Griva et al. 2000). Lower HbA1c was also associated with endorsement of fewer symptoms. Both Skinner et al. (2000) and Law et al. (2002) reported no associations between illness beliefs and glycaemic control. They did, however, report that poor glycaemic control was associated with increased anxiety levels, and in the case of the longitudinal study by Skinner et al. (2000), anxiety was a significant predictor of glycaemic control.

The results of Griva et al. (2000) gave support to the SRM which has demonstrated relationships between adherence behaviours and illness beliefs (Hagger & Orbell, 2003). The reason for the lack of positive findings is unclear. However, the study conducted by Law et al. (2002) failed to control for the minimum time since diagnosis and therefore this may be a confounder for HbA1c values as described above. Another

possibility is that although HbA1c gives an estimate of adherence, other factors such as physiological changes during adolescence are known to affect HbA1c values.

Self-reported adherence

The results revealed consistency with regard to the association between illness beliefs and self-reported adherence. Five out of six studies found better dietary adherence to be associated with more positive beliefs about control (Griva et al. 2000; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Skinner et al. 2003). In addition, the study by Griva et al. (2000) found relationships between beliefs about control and adherence to insulin injecting, blood glucose monitoring and exercise. They reported that the only significant predictor variable from the IPQ was the perceived control subscale which accounted for 39% of the variance in self-reported adherence (Griva et al., 2000).

With regard to self-reported adherence the evidence would suggest that this is related to illness beliefs and that these relationships are in keeping with the SRM. One difficulty in the assessment of self-reported adherence is that it depends on an accurate response from participants who are subject to distortion and response biases. However, the consistency between studies suggests that self-reported adherence can be a valid measure.

Self-efficacy

Griva et al. (2000) was the only study to explore the relationship between self-efficacy and illness beliefs. This study found the stronger the beliefs about perceived control over diabetes the higher the level of self-efficacy. Self-efficacy beliefs were

negatively associated with beliefs about identity, indicating that endorsement of fewer symptoms was related to higher levels of self-efficacy. Finally, high levels of diabetes self-efficacy were associated with positive beliefs about the consequences of diabetes. These results require validation by further studies in this area. This study was of a 'high' quality however adolescents and young adults were combined. Replication within a purely adolescent sample would be desirable.

Psychological morbidity/ psychological well-being

The results of all six studies revealed a consistent relationship between illness beliefs and aspects of psychological well-being. Higher reported anxiety was associated with more negative beliefs about the consequences of diabetes. (Edgar & Skinner, 2003; Skinner & Hampson, 1998; Skinner et al. 2000; Skinner & Hampson, 2001; Law et al. 2002; Skinner et al. 2003). Anxiety was also found to be related to beliefs about illness identity, anxiety ratings increasing as the number of symptoms identified as part of the disease increases (Skinner et al. 2003). More positive beliefs about perceived control were related to higher levels of well-being (Edgar & Skinner, 2003; Law et al. 2002).

The measure used for psychological well-being and psychological morbidity was the WBQ (Bradley, 1994). This measure was not originally intended for use with adolescent populations and its extensive use with this population underlines the problem of a lack of diabetes specific measures for use with adolescents with diabetes. Some of the studies reported that they adapted the scales for use with this population but it is not clear if these adaptations were consistent across studies.

Withstanding this criticism, results supported the relationship between illness beliefs and psychological morbidity and well-being.

3. What is the relationship between social factors and illness representations?

The three studies which explored the relationship between social factors and illness beliefs did so by disparate methods. The longitudinal study (Skinner & Hampson, 1998; Skinner et al., 2000) found that increased levels of social support were related to positive beliefs about control. The third study by Law (2002) demonstrated that maternal and adolescent participants differed significantly in their beliefs on only two dimensions; consequences and emotional impact.

The small number of studies makes generalisability of these results to the wider adolescent population difficult. In particular the study by Law (2002) relied on a small sample and as such it is possible that it did not have sufficient power to detect differences between the illness beliefs held by adolescents and their mothers. Such studies require replication to establish the role of social factors in the illness beliefs of adolescents.

Questionnaire and methodological considerations

Measures of illness beliefs

Although different questionnaires were used, all were based on the SRM and comparison between studies was not unduly hindered by these differences as the dimensions being measured were consistent. However, studies did not clearly report which dimensions of the respective illness belief measures were included.

Measures of psychological well-being

As discussed above the WBQ has not been validated for use with adolescents. Skinner & Hampson (1998) reported pilot data which suggested younger adolescents had difficulties understanding the positive well-being and energy subscales. (Skinner & Hampson, 1998). Other studies did not report such difficulties nor did they report that the measure was adapted or altered for use with an adolescent population.

Specificity of methodological descriptions

The methodology of the studies was well defined with explicit inclusion and exclusion criteria. Refusal and drop out rates were described in all studies. The studies reported by Skinner and colleagues (Skinner & Hampson, 1998; Skinner et al., 2000; Skinner & Hampson, 2001) represented a single sample followed longitudinally over three time points. Whereas, the study by Skinner et al. (2003) was a collection of 4 studies published within one paper, each study having different samples.

Failure to control for mediating and confounding variables

Most of the studies recruited from a convenient sample of outpatients attending their regular diabetes clinic appointment. Only one study (Griva et al. 2000) reported demographic data on non participants.

One study recruited participants via the Diabetes UK membership by postal survey (Skinner et al. 2003). The problems associated with postal survey are multiple and well-recognised including low response rates, missing data and reduced

representativeness. Furthermore diabetes UK members are unlikely to be representative of those with type 1 diabetes.

Age Range

Finally, a major difficulty with the studies was the age range considered to be 'adolescent'. Broad age ranges from 11-18, or 12-19 years were included. Given the physiological, emotional, cognitive and social developments during adolescent years it is probable that younger adolescents are not at the same stage of development in any or all of these areas as older adolescents and this may be a major confounding variable not currently taken into consideration in this area of research. Related to this is that younger adolescents may continue to have more intensive support with their diabetes management from family and parents who may continue to have a direct role in this area.

Conclusions

This systematic review of the literature concerning the illness beliefs of adolescents with Type 1 Diabetes is, to the best of our knowledge, the only review of this area. The results demonstrated that illness beliefs were related to a number of variables including demographics, self-reported adherence to treatment, self-efficacy, psychological well-being and social factors. Illness beliefs were not consistently related to physiological adherence as measured by HbA1c however other physiological changes taking place during adolescence may act as confounding variables.

There was consistency across studies in findings related to associations between illness beliefs and psychological well-being and self-reported adherence to treatment. In the case of the relationship between illness beliefs and physiological adherence this relationship was less clear with only one study reporting such a relationship. There was a paucity of research exploring relationships between illness beliefs and social factors or self-efficacy. These areas therefore require further investigation.

A variety of factors may account for the inconsistencies found between studies including the use of different questionnaires to measure illness beliefs and clinical and demographic variables uncontrolled for such as time since diagnosis. However, the literature to date does give some support to the Self-Regulatory Model (Leventhal et al., 1980). Future studies exploring adolescent illness beliefs of Type 1 diabetes may consider the points outlined in Table 4.

*** Insert Table 4 ***

Given the growing evidence of the application of the Self-Regulatory Model to chronic illnesses such as Type 1 diabetes in adults, and its ability to inform health professionals of the nature of the relationship between illness beliefs and health outcomes, further research in adolescence is required. Research into adolescent illness beliefs could usefully inform clinical interventions to promote positive health outcomes in this vulnerable and important group.

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Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">1) Adolescent participants aged 11-19 years2) Diagnosis of Type 1 Diabetes Mellitus3) Assessment of Illness Representations by recognised method e.g. IPQ-R, PMDI.4) Outcome measures including adherence or well-being or self-efficacy or self-care.	<ul style="list-style-type: none">1) Paper not available in the English language2) Dissertation abstract3) Single Case Design4) Descriptive studies with no manipulation of data5) Book chapters6) Letters or comments

Table 2: Excluded studies

Reason for Exclusion	No. Excluded	References
The article did not include children or adolescents or combined an age range out with inclusion criteria for review	6	(Hampson et al. 1990; Hampson, 1997; Lange & Piette, 2006; Lawson, et al. 2004; Skinner et al., 2005; Brownlee-Duffeck et al., 1987)
The study did not use a measure of illness representations	3	(Stewart et al., 2003; Wing et al. 1986) (Leung et al., 1997)
Book chapter and review	1	(Petrie et al. 2003)
The article was a review or descriptive only and did not involve any comparisons or experimental manipulation	1	(Caban & Walker, 2006)
Dissertation abstract	2	(AlAkour, 2003) (Copp et al. 1998)

Table 3: Summary of studies addressing illness representations in an adolescent population

Authors	N (Male: Female)	Age	Duration of diabetes	Methods and Measures	Main Results	Methodological Problems
Edgar & Skinner (2003)	70 OP 40:30	11-18 X=14.1	X=3.8	DIRQ WBQ – amended – 3 sub-scales KIDCOPE	Perceived impact and identity correlated with all 3 well-being indices. Treatment effectiveness measures correlated with positive well-being not anxiety/ depression. Cognitive restructuring (coping measure associated with less depression and higher positive well-being. Association between cognitive restructuring and positive well-being mediated by treatment effectiveness beliefs.	Retrospective gathering of coping self report data. No power calculation No data about non-participants; response rate = 56%
Skinner et. al. (2003) Study 1	115 (young diabetics of Diabetes UK) 27% male response rate = 9%	12-18 X=16.9	X=6.8+4.6	2 scales of the IPQ modified – Perceived consequences Perceived effectiveness of treatment SDSCA Medical treatment data	Treatment effectiveness to prevent complications sig. r with diet. Treatment effectiveness to control diabetes sig. r with diet and blood glucose monitoring. Higher beliefs in treatment effectiveness assoc. with better self-care. Neither perceived impact nor perceived threat r with self- care measures.	No inclusion/ exclusion criteria. Participants may have had other chronic illness (was validation study). No data regarding time since diagnosis

Table 3: Summary of studies addressing illness representations in an adolescent population

Authors	N (Male: Female)	Age	Duration of diabetes	Measures	Main Results	Methodological Problems
Skinner et al. (2003) Study 3	44 OP 46% male	11-17 X=14.8	X=5.8+4.2	DIRQ <ul style="list-style-type: none"> • Identity • Cause • Timeline • Consequences • Treatment effectiveness SDSCA, SDQ Parents completed SDSCA & SDQ HbA1c	Older adolescents more likely to believe that diabetes is a chronic condition. Treatment effectiveness beliefs correlated with dietary self-care. And parents reported diet and exercise self-care. Greater perceived impact correlated with well-being. Identity scale not r with self-care, well-being or glycaemic control	No inclusion/ exclusion criteria. Participants may have had other chronic illness. (was validation study) No data regarding time since diagnosis
Skinner et al. (2003) Study 4	126 OP 43%	11-18 X=14.1	X=5.4+3.7	DIRQ <ul style="list-style-type: none"> • Identity • Cause • Timeline • Consequences • Treatment effectiveness WBQ - amended HbA1c	Girls more likely to believe diabetes permanent Older adolescents more likely to believe diabetes permanent and higher beliefs in treatment effectiveness. Higher socio-economic believed diabetes greater threat and treatment less effective. Perceived impact & identity assoc with all 3 well-being scales. Identity not r with HbA1c. Treatment effectiveness r with positive well-being.	No inclusion/ exclusion criteria. Participants may have had other chronic illness. (was validation study) No data regarding time since diagnosis

Table 3: Summary of studies addressing illness representations in an adolescent population

Authors	N (Male: Female)	Age	Duration of diabetes	Measures	Main Results	Methodological Problems
Law (2002)	30 OP M16:F14	13-18 X=15.5	X=4.9	IPQ-R WBQ Maternal measures IPQ-R	Higher levels of depression female subjects. Mother's beliefs rated higher emotional representations and consequences scale.	No minimal duration of illness/time since diagnosis. Small sample size Cross-sectional design so cannot infer causality. Lengthy time scale Nov-June
Skinner & Hampson, (1998)	74 OP M42:F32	12-18 X=15.18	X=4.8	PMDQ WBQ SDSCA PSS-family PSS-friends DFBC DIPS	Beliefs about consequences sig. r with depression and anxiety but not self-management. Beliefs about treatment effectiveness sig. r with dietary self-management & glucose monitoring but not anxiety/depression. Family & Friend support r with dietary self-management diabetes specific support r with blood glucose monitoring. Specific family support related to insulin injections. Family support measures sig. predictors of diet, BM monitoring and insulin injections. (more support = better self-management) Peer support and gender sig. predictor of depression. Perceived impact sig. predictor of depression and anxiety along with female gender. Perceived efficacy of treatment predictive of dietary self-management. Treatment effectiveness beliefs mediate link between family support and dietary self-management.	No power calculation reported. Co-morbid illness not controlled for.

Table 3: Summary of studies addressing illness representations in an adolescent population

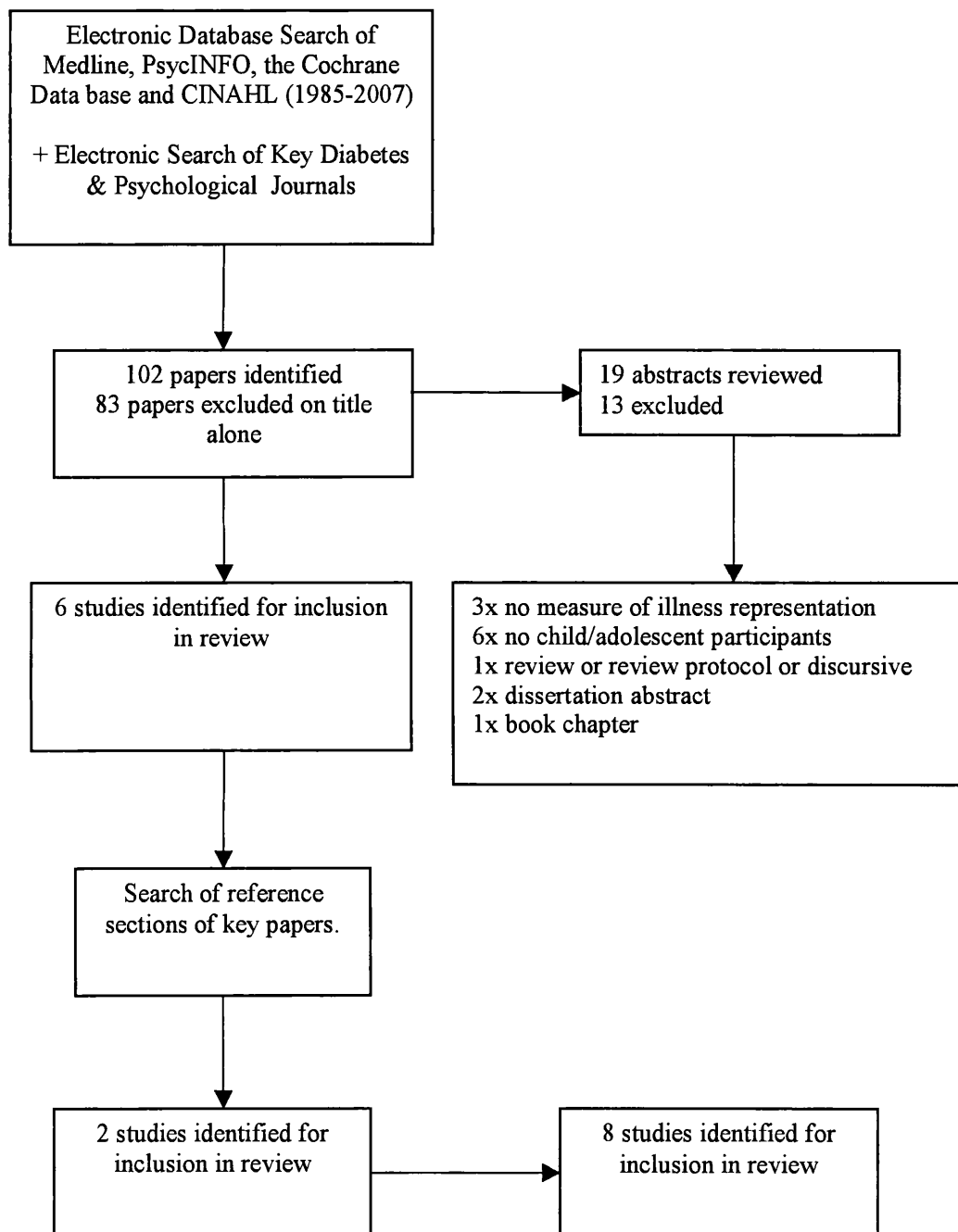
Authors	N (Male: Female)	Age	Duration of diabetes	Measures	Main Results	Methodological Problems
Law, et. al. (2002)	30 16:14	13-19 X=15.5	 X=4.9	IPQ-R WBQ SDSCA HbA1c	HbA1c assoc. with higher anxiety. Female higher levels of depression. Consequences and personal control predictors for anxiety and positive well being. Dietary management and insulin admin. Assoc. with HbA1c.	No power calculation Lack of power due to small sample size. Regression analysis but small numbers. No minimal time since diagnosis set as exclusion criteria.
Skinner, John & Hampson (2000)	52 OP 28:24	12-18 X=15.6	 X=5.9	PMDQ WBQ SDSCA PSS-family PSS-friends DFBC DIPS	Higher perceived impact assoc. with poorer well being. Perceived treatment effectiveness predictive of better dietary self-care.	Co-morbid chronic illness not as exclusion criteria. No power calculation.
Griva, Myers & Newman (2000)	64 OP 31:33	15-19* X=17.19 20-25** X=23.16	X=7.91 (4.67)	IPQ GSE SEDS Adapted BMQ HbA1c	Illness beliefs and self efficacy beliefs may be useful predictors of adherence and metabolic control.	No power calculation Cross section so cannot make causal attributions.
Skinner & Hampson (2001)	54 OP 22:32	12-18 X=15.18	 X=4.8	PMDQ SDSCA HbA1c WBQ	Changes in perceived impact prospectively predicted anxiety. Changes in perceived treatment effectiveness predicated dietary self- care. Poorer dietary self-care and female predicted poorer glycaemic control.	Co-morbid chronic illness not as exclusion criteria. No power calculation.

* Adolescent participants were analysed separately from ** young adults to ascertain any differences. No differences were found and analysis thereafter combined adolescent and young people

Table 4: Summary of methodological and design features for consideration in future studies

Recommendations for future studies exploring the role of illness beliefs in adolescents with Type 1 diabetes
<ul style="list-style-type: none">• Validated measure of illness representations specific to diabetes• Researching illness beliefs of younger and older adolescents.• Outcome measures which are diabetes specific and validated for use with adolescents where possible• Inclusion of a power calculation to assist with sample size.• Longitudinal study design to establish direction of causality between illness beliefs and outcome variables• Inclusion of potential confounding variables such as age at diagnosis and duration of illness• 6 months to 1 year as minimal time since diagnosis as inclusion criteria.

Figure 1: Flow chart demonstrating process and results of systematic search strategy



CHAPTER 3

MAJOR RESEARCH PROJECT PROPOSAL

Similarity of adolescent and maternal illness representations of Type 1 diabetes: Its relationship to self-management, self-efficacy, well-being and adherence to treatment in adolescents with diabetes.

Summary

Adherence to treatment for Type 1 diabetes is central to minimising serious short-term and long-term complications of the disease. Adolescence is a time when responsibility for diabetic control is being transferred from the parent to the child and poses a number of challenges for the adolescent, the parent and the diabetes team. Illness representations have been shown to be important determinants of well-being, self-management and adherence to medical regimes. However little research has focussed on either the illness representations of the child or adolescent or how these compare with illness representations of the parent. The aims of this study are to (1) measure the congruence between the illness representations held by adolescents who have diabetes and their mothers and (2) to explore its relationship to adolescent well-being, self-management, self-efficacy and adherence to the diabetes treatment regime. Using a cross sectional design, adolescents with diabetes, aged 12-15 years inclusive, and their mothers will be recruited. Each adolescent will complete measures of illness representation, well-being, self-efficacy and self-management. In addition, adherence will be measured using both physiological and self-report measures. Maternal subjects will complete a measure of illness representation. Power calculations indicate a sample size of 30 subjects in each group. The importance of good glycaemic control cannot be overstated. This study aims to determine the level of congruence between maternal and adolescent illness representations. We know from the adult literature that incongruence of illness beliefs has a negative impact on psychological well-being and adherence. We intend to explore its relationship to self-management, self-efficacy, well-being and adherence. If there are significant relationships between these variables then congruence of illness representations may become an important area for both clinical intervention and future research.

Introduction

Type 1 diabetes, also referred to as insulin dependent diabetes mellitus, is a chronic, life long condition the onset of which is often in childhood or adolescence. It has a prevalence of 1% and in Scotland there are currently approximately 1800 children under the age of 15 years on the Scottish Study Group register. Successful management of Type 1 diabetes requires adherence to a complex and demanding treatment regimen involving; diet, exercise, blood sugar monitoring, insulin dose manipulation and administration by subcutaneous injection. Adherence to this regime is paramount to avoid medical emergencies such as diabetic ketoacidosis and hypoglycaemia. Adherence is also important to minimise future complications related to poor glycaemic control such as peripheral neuropathy, nephropathy, retinopathy and heart disease. The central importance of tight glycaemic control in reducing the risk of these complications has been demonstrated in The Diabetes Control and Complication Trial (DCCT, 1993) which found a direct relationship between glycaemic control and physical health risk reduction, both in the group as a whole and the adolescent sub-group. For adolescent subjects randomised to receive intensive therapy this resulted in improved blood glucose control in the group as a whole, and this improvement was sustained over a mean period of 7.4 years (Wolfsdorf, 1999). Despite being prescribed intensive insulin therapy many adolescents fail to achieve treatment targets. The importance of psychological factors related to self-management is being increasingly recognised and has been the focus of much research.

The Self –Regulatory Model (SRM)

Advances in health psychology have contributed much to research in this area. In an attempt to measure how people describe and respond to health related stressors, Leventhal and colleagues developed the Self- Regulatory Model (SRM) (Leventhal, et al. 1980; 1984). Research using this model has highlighted the importance of people's perceptions of their illness and its relationship to subjective well being, self-management and adherence to medical regimes (Paschalides et al. 2004; Scharloo et al. 1997). To date there has been little research concentrating on the illness representations of children and adolescents. In a longitudinal study, Skinner & Hampson (2001) used the framework of the SRM to examine the illness perceptions of adolescents with Type 1 diabetes. Using the Personal Models of Diabetes Interview, they found illness representations to be important predictors of dietary self-care and psychological well being (Skinner & Hampson, 2001). In particular they found that beliefs about the effectiveness of treatment to control diabetes were predictive of better dietary self-care. They concluded that "the more adolescents believe their treatment regime will control their diabetes, the better their subsequent dietary self-management will be" (Skinner & Hampson, 2001, p832) and that better dietary self-management is associated with better glycaemic control. They also found that the greater the impact the adolescent perceives diabetes to have on their life then the more anxiety they subsequently experience (Skinner & Hampson, 2001).

In addition to there being little research addressing child and adolescent illness representations there has also been a paucity of research concerning illness beliefs and representations of parents involved with the care of the adolescent with Type 1 diabetes. The need to extend the Self Regulatory Model into the social context of the

individual has been identified and acknowledged as an important area of future research to help to understand how illness representations are developed (Leventhal et al. 1998, cited in Law, 2002).

To date, little is known about how illness representations form. One hypothesis put forward by Lau et al. (1990) is that parents may influence the illness representations and health related behaviours of their children. It has also been proposed that when coherence of illness beliefs is lacking because people do not share a common illness model, then adherence and psychological well-being will be affected (Kleinman, 1980). The findings of a number of studies from the adult literature give support to this. In a study comparing the illness beliefs of patients and their partners about psoriasis, divergent beliefs were reported to be associated with increased psychological distress (Richards et al. 2004). Heijmans et al. (2001) compared the illness representations of patients and their GP and reported that incongruence was associated with a worse health status and an increase in health care use.

A recent study addressed the issue of maternal and adolescent illness representations and examined the relationship to well-being. The subjects were 30 adolescents (13-19 years) with Type 1 diabetes and 26 mothers. The adolescent subjects completed the Illness Perception Questionnaire – Revised and the Well Being Questionnaire as part of an extensive battery of questionnaires. The mothers completed the Illness Perception Questionnaire – Revised. Significant differences were found between maternal and adolescent illness representations on two dimensions: consequences and emotional representations. The reported means and standard deviations, in brackets for these dimensions are as follows: For the consequences dimension adolescent mean

2.27 (0.61) maternal mean 2.74 (0.62) and for the emotional representations dimension adolescent mean 2.22 (0.77) maternal mean 2.76 (0.94). This study reported a high degree of consistency in the beliefs held by adolescents and their mothers. The author states that “such congruence is presumed to benefit psychological well-being though no relationship between maternal beliefs and well-being was found” (Law, 2002, p375). It has been suggested that maternal illness beliefs might be channelled into different areas of individual or family behaviour. In a study of adolescents with diabetes it was reported that the adolescents’ illness representations were not predictive of insulin injecting or blood glucose monitoring (Skinner & Hampson, 2001). One possible explanation, proposed by the authors, to account for these results is the importance of parental involvement in these behaviours thus leaving no room for the involvement of adolescents’ illness representations. This is likely to be especially true for younger adolescents who may not yet have total control over their diabetes management and may still be prompted or helped by their parents. They proposed that “beliefs can predict behaviour only when the individual has responsibility for the activities concerned” (Skinner & Hampson, 2001, p833)

Given the lack of clarification surrounding the development and role of illness beliefs, and how they relate to outcome measures such as well being, self-management and adherence, we propose to extend the work done by Law (2002). Unlike the Law study we intend to use a narrower age band 12-15 year inclusive. The reason for this being to minimise the risk of confounding any results by treating older and younger adolescents as a homogenous group, given the developmental, social, cognitive and psychological differences found between younger and older adolescents. We therefore propose to examine the congruence between adolescent and maternal illness

representations and how this relates to behaviours central to diabetes management, self-efficacy, adolescent well-being and adherence to the diabetes regime.

Aims & Hypotheses

- To establish if there are significant differences between maternal and adolescent illness representations of Type 1 diabetes.
- To explore the relationship between incongruent adolescent and maternal illness representations and self-management, self-efficacy, adherence and well-being in adolescents with diabetes.
- Significant differences between maternal and adolescent illness representations of diabetes will be negatively associated with (1) self- management, (2) self-efficacy (3) well-being and (4) adherence in the adolescent with Type 1 diabetes.

Methods

Participants

The sample will be recruited from the diabetes out patient clinic at the Royal Hospital for Sick Children, Yorkhill, Glasgow. All adolescent out patients attending outpatient clinics will be eligible for inclusion if they meet the following criteria:

1. diagnosis of Type 1 diabetes for at least 1 year
2. aged 12-15 years inclusive
3. No known co-morbid medical condition e.g. cystic fibrosis
4. English as first language
5. The mother of the young person aged 12-15 years. (It has been observed (Law, 2002) that mothers are those who usually attend for appointments with their child. For this current study fathers are excluded as the number

of fathers actually attending with their child is expected to be very small and their inclusion may act as a confounding variable. This is not to say that paternal illness representations are in anyway less important and does merit study however the scope of the present study does not allow for their inclusion.

Written informed consent will be obtained from the adolescent and mother who agree to participate (see appendices 3.3 & 3.4).

Recruitment

Out patient appointments for adolescents attending the diabetes clinic will be obtained via the diabetes team at RHSC. Contact will be made with parents via a letter informing them of the study with the option to participate. The content of the letter will introduce the subject of the study in positive terms that is, factors which may help adolescents to manage their diabetes effectively. An information sheet on the purpose and method of the study will be provided for both parent and adolescent (see appendices 3.1 & 3.2).

Measures

Illness Perception Questionnaire – Revised (Moss- Morris et al., 2002)

This will be used to measure the dimensions of adolescent and maternal illness representations. Patients cluster their ideas about an illness around five coherent themes, which together form the patient's perception of their illness. The major cognitive themes are;

1. Identity- which is comprised of the label of the illness and the symptoms the patient views as being part of the disease
2. Cause – personal ideas about aetiology which may include simple single causes or more complex multiple causal models
3. Time-Line – how long the patient believes the illness will last, categorised as acute, chronic or episodic
4. Consequences – expected effects and outcome of the illness
5. Cure / control – how one recovers from or controls the illness.

The IPQ – R assesses perceptions on each of the above five dimensions by asking patients for their own beliefs about their condition.

In accordance with the Law (2002) study three additions will be made to the IPQ-R:

1. The first part of the questionnaire measures illness/identity and consists of 12 core symptoms. A further 6 symptoms common to diabetes (sore throat, wheeziness, weight gain, thirst, shakiness, passing a lot of urine) will be added.
2. Three items will be added to the IPQ – R ‘consequences’ scale (‘my friends treat me differently because of my diabetes’; ‘my diabetes has serious social (friendship) consequences’; ‘I worry about telling people about my diabetes’). The rationale given by Law for these additions is that research identifies these as core areas related to the psychosocial consequences of adolescent diabetes.

3. Two items will be added to the 'emotional representations' subscale; 'my diabetes makes me feel different from other people' and 'I worry about my future health and well being'.

The IPQ-R will be adapted to measure maternal illness representations specific to diabetes as described by Law (2002). 'My diabetes...' will be replaced with 'my son/daughter's diabetes....'

The Hospital Anxiety and Depressions Scale

The Hospital Anxiety and Depressions Scale (Zigmond & Snaith, 1983) is a brief self report measure consisting of 14 items on 2 subscales (7 items for anxiety and 7 items for depression). Construct and concurrent validity have been demonstrated in physically ill populations and for use with adolescents (White, 1999)

Visual Analogue Scale (VAS) –to measure self-efficacy

The VAS is extensively used as a self-report and observational measure. It consists of a 100mm line that pictorially represents two behavioural extremes at either end of the continuum that is, not confident (score 0) and very confident (score 100). Reliability of the VAS is in the moderate to high range (0.61 – 0.73) (Weinman et al. 1995).

Measures of adherence

The Summary of diabetes self care activities (Toobert & Glasgow, 1994)

This is a 12 item self-report instrument that measures four areas of diabetes self-management and adherence; diet, exercise, blood glucose monitoring and injecting-

medication taking over the previous 7 days. Well validated and used both with adults and adolescents (Skinner et al. 1998).

Blood Glucose Meter Data

Frequency of checking blood sugar levels during the past week will be downloaded from the participants Blood Glucose Meter to a lap top, no patient identifiers will be included.

Hypoglycaemia

Frequency of symptomatic hypoglycaemia over the last 4 weeks will be recorded. Frequency of severe hypoglycaemia (defined as a hypoglycaemic episode requiring assistance) over the last 4 weeks will be recorded by self report.

Glycaemic control

At each out patient appointment HbA1c is measured and reflects the average level of blood glucose over the past 2-3 months. This data will be collected via the on-line data system.

In addition to the above, demographic information will be collected including duration of illness, age at onset of diabetes, age, gender, and ethnicity. This information will be collected from the computerised record of children attending the diabetes service at RHSC.

Design and Procedure

The design to be used is cross sectional, quasi experimental in that differences between maternal and adolescent illness representations (independent variable) are considered and their relationship to the dependent variables; self-management, self-efficacy, well-being and adherence are explored. Participants will be given the questionnaire pack at their out patient appointment. There will be a room available to complete the questionnaires or alternatively they can complete them at home and return them in a prepaid envelope to the Section of Psychological Medicine (this will help to reassure participants of the confidentiality of their responses from the diabetes team).

Settings and Equipment

The setting for the study is the Royal Hospital for Sick Children, Yorkhill NHS Trust, Glasgow. The out patient department will be the site of administration of the questionnaires or alternatively the participants can take them home to complete and return them in a pre paid envelope.

A supply of A3 envelopes and stamps and adequate copies of a letter inviting participation as well as parent/ adolescent information sheets both on headed notepaper from the Department of Psychological Medicine will be required. The IPQ-R, the Summary of Diabetes Self-Care Activities and the HADS have the right to be reproduced. Access to a laptop to download meter readings would be advantageous.

Power Calculation

In order to calculate sample size a power calculator was used (www.caclulators.stat.ucla.edu/powercalc). In line with convention, alpha of 0.05 (two tailed) and power of 0.8 will be set. Mean and standard deviations for the groups were obtained for the IPQ-R from the reported results of Law, 2002. The values used were those obtained on the dimensions where significant differences between maternal and adolescent representations were found, namely consequences (adolescent mean 2.27 (0.61) maternal mean, 2.74 (0.62) and emotional representations (adolescent mean 2.22(0.77) and maternal mean 2.76(0.94). Using these values a sample size of 29.835 was obtained. This will be rounded up to 30 participants for each group.

Data Analysis

This will involve, descriptive statistics, checking the data for normality, computation of t-tests to ascertain any differences between maternal and adolescent responses on the IPQ-R. Pearson's correlations will be computed to explore associations between variables.

Practical Applications

Referrals will come from the diabetes team at the Royal Hospital for Sick Children, Yorkhill for children attending for review at outpatient appointments. Parents and adolescents will be invited to participate in the study by letter and information sheets will be sent informing the parent and adolescent of the purpose and method of the study. Completion of the questionnaires should take approximately 20 minutes for the adolescent participants and 10 minutes for the mothers.

The importance of good glycaemic control cannot be overstated. This study aims to determine the level of congruence of illness representations held by both mother and adolescent and to explore the relationship with self-management, self-efficacy, well-being and adherence. If these are significantly related then congruence of illness representations may become an important area for both clinical intervention and future research.

Timescale

Submission of proposal to Local Research Ethics Committee – **June 2005**

Preparation of materials for research – **July 2005**

Data collection – **October 2005 – December 2005** - A short period is indicated in research with diabetes due to seasonal variation with better diabetic control being reported in the summer months. This time period will also allow for the majority of adolescents with diabetes attending for appointment to have the chance to participate in the study.

Data Analysis and Write-up – **April 2007 – June 2007**

Final Draft to supervisor – **June 2007**

Ethical Approval

This proposal will be submitted to Greater Glasgow NHS Trust Ethics Committee for assessment. An application for ethical approval will also be sent to Yorkhill NHS Trust.

Possible Ethical issues

1. Possible stress for the adolescent and mother by filling out questionnaires. –
Hopefully kept to a minimum by keeping number of measures to be completed to a minimum and option of where they are completed i.e. clinic or at home.
2. Confidentiality: Participants may be concerned that the answers they provide may be available to the diabetes team. Explanation that all information is confidential and will not be shared with wider team. Also, participants will be identified by code not by name on any measure.
3. The HADS may demonstrate specific problems such as anxiety / depression: If this situation does arise then discussion with the named supervisor will take place and if appropriate the participant or the parent of the participant will be encouraged to speak with their GP or appropriate member of the diabetes team.
4. Disclosure of sensitive/ important information – such incidents if occurring shall be discussed fully with research supervisor and appropriate action taken.
5. The exclusion of fathers from the study may cause concern.

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CHAPTER 4

MAJOR RESEARCH PROJECT

Maternal and adolescent illness beliefs about diabetes: An exploratory study of its relationship to adolescent adherence, self-efficacy and psychological well-being.

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Prepared in accordance to requirements for submission to Diabetes Care (Appendix 4.1)

Abstract

Objective

To establish if there are significant differences between maternal and adolescent illness representations of Type 1 diabetes and explore their relationship with self-management, self-efficacy, adherence and well-being in adolescents with diabetes

Research Design and Methods

Cross-sectional, within subjects correlational design outpatient based questionnaire survey of adolescents aged 12-15 with type 1 diabetes, diagnosed for at least one year, and their mothers. 41 subjects and their mothers completed questionnaires relating to their illness perceptions. Adolescents completed measures assessing psychological morbidity, self efficacy and adherence. Glycaemic control was assessed by HbA1c, 14 day mean self monitored blood glucose readings and self-reported hypoglycaemia.

Results

The response rate was 53%. The mean age of the adolescents was 13.0 years and duration of diabetes 4.9 years. Mothers viewed their child's diabetes as having more serious consequences and a higher emotional impact. Dissimilarity between adolescent and maternal illness perceptions was associated with higher levels of anxiety. No effect of 'dissimilarity' was found with regard to self-efficacy, adherence or self-management however anxiety was associated with poor glycaemic control.

Conclusions

Illness representations between adolescent and mother can be significantly different and that dissimilarity or a lack of shared illness representation between mother and adolescent can be detrimental to psychological well-being. Consequent adverse effects on glycaemic control may be seen.

Diabetes

Type 1 diabetes is a chronic medical condition often diagnosed in childhood and adolescence. The annual incidence of childhood onset type 1 diabetes in the United Kingdom is high at approximately 20 per 100,000 population and has risen dramatically over the last 30 years (1). The aim of treatment is to maintain blood glucose levels as near normal as possible without causing hypoglycaemia. This requires a demanding and intensive treatment regime involving blood glucose monitoring, insulin injections, adherence to a healthy balanced diet and exercise regime. Optimal adherence to the regime and maintenance of tight blood glucose control has been demonstrated to reduce the serious complications of diabetes both in the short and long-term. (2)

Factors associated with adherence in adolescents with diabetes

Given the importance of adherence to treatment there has been much research within the health psychology literature to identify factors which influence adherence. Factors such as psychological well-being, treatment satisfaction, self-efficacy and quality of life (3,4) have been found to be important determinants of adherence. There has also been a great deal of research addressing the role of social factors in adolescent adherence. This research has concentrated on both the role of the family (5-9) and peers (10) and findings suggest that supportive family and friends are related to better adherence.

The Self-Regulatory Model (SRM)

The SRM, also referred to as the 'common-sense model of self-regulation of health and illness' or CSM is a theoretical model that addresses how cognitive factors

influence coping behaviours and outcomes for people experiencing a health threat (11-13). The SRM has been applied extensively to chronic illness populations. A recent meta-analysis of the SRM (14) concluded that there was evidence for theoretically predictable relations between illness cognitions, coping and outcomes across studies.

The SRM proposes that illness representations are guided by three main sources of information: the first source is from a pool of general information that the individual has assimilated from previous social communication and cultural knowledge of the illness. The second source of information is derived from significant others such as a doctor or parent and the third source is based on current and past experiences of the illness. As such the “family provides the earliest context for the acquisition of explicit memories and implicit skills for the exploration, labelling and management of symptoms... (and) creates an interpersonal context for developing cognitive representations of illnesses” (15). The nature of illness representations are therefore based very firmly within the social environment.

Social context of illness representations

Given the importance of the social context of illness representations a number of studies have attempted to explore the relationship between illness representations held by significant others and the adherence and health outcomes of patients with chronic illness. In a large study of patients with either diabetes or osteoarthritis, Heijmans et al. (16) compared patients’ perceptions about their disease with the perceptions of their GP. They found that incongruence in beliefs between the patient and their GP was associated with worse health status and an increase in health care use (16).

Richards and colleagues (17) explored the illness representations of patients with psoriasis and compared them to the illness representations of their partners. This study found that dissimilarity in illness representations were associated with increased psychological distress for both the patient and the partner of the person with psoriasis. The results illustrated the importance of concordance between patient and partner illness beliefs in relation to adjustment (17).

Parent and child illness beliefs

Within the child and adolescent literature there is a paucity of research addressing parental illness beliefs about their child's chronic illness. Yet, considering the SRM, parents would be a major source of information for which children and young people would then use to form their own illness beliefs. Salewski et al. (18) explored the illness representations of families of adolescents with a chronic skin condition and reported differences between all family members' illness representations. It also demonstrated that when families have a high level of congruity between the illness representations of both parents then adolescents reported more psychological well-being (18). Law, (19) explored the differences between adolescent illness beliefs about diabetes and the illness beliefs of the mother and found that adolescent and maternal illness representations significantly differed on two dimensions. Mothers perceived their child's diabetes as having more serious consequences and as having a greater emotional impact than their child. In contrast to the study by Salewski et al. this study found no relationship between similarity of illness representations and the psychological well-being of the adolescent (19).

Given both the paucity of research in this area and the inconsistent findings, the current study aims to replicate and extend the work by Law (2002). Using a cross-sectional design the illness representations of adolescents with Type 1 diabetes and their mothers are compared and their relationship to psychological well-being, adherence, and self-efficacy explored (See figure 4.1 for a diagrammatic representation.)

*** Insert Figure 1 ***

Aims

- To establish if there are significant differences between maternal and adolescent illness representations of Type 1 diabetes.
- To explore the relationship between similarity of adolescent and maternal illness representations and self-management, self-efficacy, adherence and well-being in adolescents with diabetes.

Hypothesis

- Significant differences between maternal and adolescent illness representations of diabetes will be associated with 1) poor self- management, 2) low self-efficacy, 3) poor psychological well-being and (4) poor adherence in adolescents with Type 1 diabetes.

Research Design and Methods

Design

To investigate this hypothesis, this study followed a cross-sectional, within subjects correlational design.

Participants

Participants were recruited from the diabetes out-patient clinic at the Royal Hospital for Sick Children, Yorkhill, Glasgow. Criteria for inclusion in the study were:

1. Diagnosed with Insulin Dependent Diabetes Mellitus for at least 1 year;
2. Aged 12-15 years inclusive;
3. No known co-morbid medical condition, for example cystic fibrosis;
4. Able to complete the measures with only minimal assistance;
5. English as first language; and
6. The mother of the young person with Type 1 diabetes attending clinical appointments.

The last criteria was used because it has been observed (19) that mothers usually attend appointments with their child. The diabetes team at Yorkhill were of the opinion that very few fathers attended out-patient appointments. Fathers were therefore excluded from the current study, as their inclusion could potentially act as a confounding variable. This is not to say that paternal illness representations are in anyway less important, however the scope of the present study did not allow for their inclusion.

Power calculation

A power calculation to establish sample size was conducted. In line with convention, alpha of 0.05 (two tailed) and power of 0.8 was set. Means and standard deviations for the maternal and adolescent groups were obtained for the IPQ-R from the Law study (19). The values used were those obtained on dimensions where significant differences between maternal and adolescent representations were found, namely consequences (adolescent mean 2.27 (0.61) maternal mean 2.74 (0.62)) and emotional representations (adolescent mean 2.22 (0.77) maternal mean 2.76 (0.94)). Using these values a sample size of 30 was obtained (20).

Measures

Measure of Illness Beliefs

The Illness Perception Questionnaire – Revised (21) is a self –report measure with good discriminant and predictive validity across 8 different illness groups. Internal consistency scores are reported as 0.79-0.89(21). The IPQ-R includes 8 subscales, all of which were used in the present study: **illness identity** – the number of symptoms experienced and attributed to the illness; **timeline** – how long the illness is expected to last; **consequences** – of the illness, **personal control** – over the course of the illness; **treatment control** – the illness can be cured/ controlled by treatment; **illness coherence** – understanding about the illness; **cyclical** – the symptoms experienced recur in a cyclical fashion, and **emotional representations** – the degree of emotional response to the illness.

In accordance with Law, (19) three additions were made to the IPQ-R:

- (1) Six symptoms common to diabetes (sore throat, wheeziness, weight gain, thirst, shakiness and passing a lot of urine) were added to the Identity scale.
- (2) Three items were added to the 'consequences' scale ('my friends treat me differently because of my diabetes'; 'my diabetes has serious social (friendship) consequences'; 'I worry about telling people about my diabetes'). The rationale given by Law for these additions is that they have been identified as core areas related to the psychosocial consequences of adolescent diabetes.
- (3) Two items were added to the 'emotional representations' subscale: 'my diabetes makes me feel different from other people' and 'I worry about my future health and well being' (19).

The IPQ-R was also adapted to measure maternal illness representations specific to diabetes in accordance with Law, (19) 'My diabetes...' was replaced with 'my son/daughter's diabetes...'

Each belief statement on the IPQ-R is rated on a Likert scale of 1 = strongly disagree, to 5 = strongly agree. High scores on the identity, timeline, consequences and cyclical sub-scales are indicative of beliefs in a greater number of symptoms, chronicity, serious impact and recurring nature of the disease. In contrast, high scores on the personal control, treatment control and illness coherence sub-scales are representative of beliefs in high levels of control and personal understanding of the illness (21).

Measure of psychological morbidity

The Hospital Anxiety and Depression Scale (HADS) (22) is a brief self-report measure consisting of 14 items on 2 subscales (7 items for anxiety and 7 items for

depression). Construct and concurrent validity have been demonstrated in physically ill populations and for use with adolescents (23).

Measure of Self-Efficacy

A visual analogue scale (VAS) was used to measure self-efficacy (24). It consists of a 10cm line that pictorially represents two behavioural extremes at either end of the continuum that is not confident (score 0) and very confident (score 10). Reliability of the VAS is in the moderate to high range (0.61 – 0.73). Adolescent participants were asked to rate their confidence with regard to blood glucose monitoring, insulin administration, exercise and diet (See appendix 4.4).

Self-report measures of adherence

The Summary of Diabetes Self-Care Activities Scale (SDSCA) (25) is a 12 item self-report instrument that measures four areas of diabetes self-management and adherence; diet, exercise, blood glucose monitoring and injecting or medication taking over the previous 7 days. Internal consistency, of this instrument, measured by inter-item correlations, is satisfactory (> 0.5) (25). For the diet, blood glucose monitoring and injecting sub-scales, the self-care statements are evaluated on a Likert scale from 1 =never to 5 = always. To allow for direct comparison between the self-care behaviours measured by the SDSCA, each raw score is converted to a standardised score as follows: 1=0, 2=25, 3=50, 4=75 and 5=100. For the two statements regarding exercise, the respondent indicates on a scale of 0-7 how many days they participate in exercise. These are converted to standardised scores as follows: 0=0, 1-2 = 25, 3-4 = 50, 5-6= 75 and 7 = 100.

The total for each sub-scale is computed and divided by the number of items it is derived of, giving a standardised mean score which allows for comparison between sub-scales. For the present study, 1 item is excluded from the diabetes medication scale which asked about oral medications as the study is concerned with Type 1 diabetes only and no participants were taking oral medication to control their diabetes.

Physiological Indices of adherence

Participants' adherence to treatment was assessed using 3 measures:

1. Blood Glucose Meter data were collected to measure the frequency of checking blood sugar levels during the 14 days prior to clinic appointment. A 14 day mean blood glucose value based on these tests was also obtained.
2. The frequency of symptomatic hypoglycaemia and of severe hypoglycaemia (defined as a hypoglycaemic episode requiring assistance) during the 4 weeks previous to clinic appointment were recorded by self-report.
3. HbA1c values, which reflect the average level of blood glucose over the past 2-3 months, were collected for participating individuals. These were obtained at the clinic appointment prior to participation in the study and were part of the routine consultation. Recommended HbA1c values are below 8, and values above this indicate poor glycaemic control.

In addition to the above, demographic information and basic information about participants' diabetes was collected including age, gender, ethnicity, duration of diabetes and age at diagnosis of diabetes.

Ethical Approval

Ethical approval was obtained from Greater Glasgow NHS Trust Ethics Committee and Yorkhill NHS Trust (see Appendix 4.2) and approval was given by Yorkhill Research and Development committee (Appendix 4.3).

Procedure

Young people who met the inclusion criteria for the study were sent information sheets via the diabetes team. Those wishing to take part indicated this by returning an opt-in letter. In addition, those who failed to opt-in were able to indicate at their out-patient appointment if they wished to participate.

Written informed consent was obtained from participating adolescents and their mothers. Participants were given the questionnaire pack on arrival at their out-patient appointment. The majority of participants chose to complete the questionnaires at the clinic. This was done in a quiet room. Participants were also given the option to complete the questionnaires at home and return them in a prepaid envelope. Mothers were given the IPQ-R only. The adolescent participants with the questionnaires in the following order; IPQ-R, SDSCA, Self-efficacy visual analogue scale and HADS. Prior to completing the questionnaire packs, mothers and children were asked not to confer on their responses to the IPQ-R questionnaire.

Data Analysis

IPQ-R

Data were analysed using SPSS version 13. All data were checked for assumptions of normality prior to analysis using Shapiro-Wilks and Kolmogorov-Smirnov tests.

Three subscales of the IPQ-R – illness coherence, timeline and emotional representations were found to be significantly not normally distributed; non-parametric tests were therefore used for these. All analyses were two-tailed and the significance level was set at $p=0.05$. Missing data were excluded pairwise for comparisons. For internal reliability they were excluded listwise.

After descriptive data was assessed, internal consistency of the IPQ-R sub-scales was assessed using Cronbach's alpha (α). Associations between maternal and adolescent illness beliefs were explored using bivariate correlations (Pearson's for normally distributed data, and Spearman's rho for non-normally distributed data). Differences between maternal and adolescent illness beliefs were computed and tested for significance using paired sample t-tests for normally distributed data and Wilcoxon Signed Rank Test for non-normally distributed data.

Difference scores for maternal and adolescent illness beliefs

The method reported by Heijmans et al. was used to compute difference scores between maternal and adolescent illness beliefs (16). These were computed by subtracting the maternal mean score from the adolescent mean score for each subscale of the IPQ-R for each mother/adolescent pair. This resulted in a continuous variable being constructed for each IPQ-R subscale. Dissimilarity between adolescent and maternal scores were identified as those which were one standard deviation above or below the mean difference score for each sub-scale, a higher score either negative or positive indicating more dissimilarity. Maternal-adolescent pairs having scores one standard deviation beyond the mean were classified as 'dissimilar' and those within one standard deviation of the mean were classified as 'similar'. One-way Analysis of

Variance (ANOVA) was computed to ascertain if the similar and dissimilar groups differed on outcome measures.

Results

Demographics

126 young people met inclusion criteria for the study and 76 were attending a clinic appointment within the time scale of the study. Of these, 25 returned the slip indicating they wished to participate. A further 16 young people indicated they wished to take part in the study at their out-patient clinic appointment. This gives a participation rate of 32% of all those eligible to take part, and a 53% participation rate of all those who were attending an appointment within the timescale of the study. See Table 1 for demographic details of adolescent participants. Demographic data was not collected for maternal participants as the aims and hypothesis did not require this.

*** Insert Table 1 ***

Physiological adherence

Table 1 provides descriptive information for the measures of physiological adherence. The mean HbA1c for the group was 8.78 (1.07). There were no significant differences in HbA1c for gender. HbA1c was correlated with age of the adolescent at time of diagnosis ($r=.333$, $p<.05$) indicating that the older the child at diagnosis the higher their HbA1c and therefore the poorer their glycaemic control. 76% of participants had an HbA1c of above 8%, which is higher than that recommended. 75% of participants brought their glucose monitoring meter to their clinic appointment. A 14 day mean was available for 25 of the 41 participants and HbA1c was significantly correlated

with the 14 day mean, ($r=.489$, $p < .01$). 85% of participants recalled having episodes of hypoglycaemia in the previous 4 week period with 60% reporting having 3 hypoglycaemic episodes or less. The minority (15%) required assistance with managing these episodes of hypoglycaemia. The frequency of blood glucose monitoring was significantly positively correlated with the number of hypoglycaemic episodes in the previous four week period ($r=.401$, $p < .05$).

Adolescent psychological morbidity

The Hospital Anxiety and Depression Scale revealed mean anxiety and depression scores of 4.67 and 2.03 respectively (see Table 2). Female participants had higher mean scores for anxiety (5.71 vs. 3.44) and for depression (2.62 vs. 1.33), however these differences were not statistically significant. With regard to anxiety, 10% of participants scored within the moderate range and a further 10% within the severe range. For the depression scale 5% obtained scores within the moderate range. Anxiety and depression were significantly correlated ($r=.513$, $p < .001$). Depression was positively and significantly correlated with HbA1c ($r=.436$, $p < .01$), indicating that children who felt more depressed had higher HbA1c values and therefore poorer glycaemic control. Anxiety was significantly correlated with HbA1c ($r=.341$, $p < .05$) indicating that adolescents demonstrating higher anxiety levels also demonstrated higher HbA1c values and poorer glycaemic control.

*** Insert Table 2 ***

Adolescent self-efficacy and self-care behaviour

Results from the Visual Analogue Scales, which range from 0 to 10, demonstrated high levels of perceived self-efficacy with the following mean scores: Blood glucose monitoring = 9.18, (2.17); administration of insulin= 8.95 (2.15); Diet = 8.17 (1.83) and exercise = 8.45 (2.25). Further analysis revealed positive correlations between confidence with blood glucose monitoring and confidence with insulin administration ($r=.401$, $p<.01$). Confidence with insulin administration was significantly correlated with diet ($r=.501$, $p < .001$) and with exercise($r=.399$, $p<.01$). Confidence with exercising and diet were significantly associated ($r=.396$, $p<.01$).

Adolescents demonstrated high levels of self-care with respect to blood glucose monitoring (mean = 83.97), and insulin administration (mean 98.72) (see Table 2). 68% of participants reported participating in less than 20 minutes of exercise three times per week. Dietary adherence was modest, with a mean of 66.51. Dietary adherence and exercise were significantly correlated ($r=.338$, $p<.05$).

Adherence to recommended diet was significantly related to confidence in knowing what to eat ($r=.351$, $p<.05$). Adherence to an exercise regime was significantly related to confidence in knowing how much to exercise ($r=.363$, $p<.05$). Blood Glucose monitoring as a self-care behaviour was negatively related to depression ($r=-.457$, $p<.001$), indicating that higher depression scores were associated with less frequent blood glucose monitoring.

Illness Representations

Internal consistency of the IPQ-R ranged from .542 to .828. Analysis of the intercorrelations between the sub-scales of the IPQ-R revealed that for the adolescent participants, emotional representations were positively correlated with beliefs about consequences ($r=.515$, $p<.001$); that is the greater the emotional impact of diabetes the greater the consequences believed to be associated with it. Emotional representations were also correlated with beliefs about the cyclical nature of the disease ($r=.430$, $p<.01$). Finally, illness coherence was negatively correlated with consequences ($r=-.325$, $p<.05$) indicating that high levels of knowledge about the disease are associated with beliefs in fewer consequences of diabetes.

Analysis of intercorrelations between the subscales of the IPQ-R for maternal participants revealed significant correlations between the cyclical subscale and the consequences sub-scale ($r=.451$, $p<.01$), personal control ($r=.347$, $p<.05$) and emotional representations of diabetes ($r=.377$, $p<.05$). In addition, emotional representations of diabetes were significantly correlated with consequences of diabetes ($r=.377$, $p<.001$).

Table 3 shows descriptive data for the IPQ-R subscales for maternal and adolescent participants.

*** Insert Table 3 ***

Mean scores for each group revealed that they view type 1 diabetes as a chronic condition, with moderate consequences and suggested strongly held positive beliefs about both treatment and personal control of the disease. Maternal and adolescent

participants showed good understanding and little confusion about the disease. They did not view diabetes as cyclical in nature. Both maternal and adolescent participants accurately identified a moderate number of symptoms they associate with the disease.

The causes subscale of the IPQ-R details a number of possible causes including hereditary, personality factors, stress etc. The items for this scale are not summed but analysed separately to ascertain beliefs about the possible causal factors of the disease as per the authors' instructions (21). Analyses of adolescent and maternal beliefs about the causes of diabetes are presented in Table 4.

*** Insert Table 4 ***

IPQ-R Intercorrelations

Analysis of maternal and adolescent illness beliefs revealed a significant relationship on the identity subscale ($r=.567$, $p<.001$).

Differences in adolescent and maternal illness representations.

Mothers were significantly more likely to see their child's diabetes as being of a more chronic nature ($z=-4.35$, $p<.001$), to have more negative consequences for their child ($t =-3.56$, $p<.000$) and for symptoms to recur ($t=-3.41$, $p<.01$). In addition, mothers demonstrated a more strongly held belief than adolescents that diabetes had a higher emotional impact on their child ($z=-5.31$, $p<.001$). Results obtained from responses on the personal control dimension revealed that mothers see their child's diabetes as more under their child's personal control than their child does ($t=-5.21$, $p<.001$).

Finally, maternal and adolescent ratings of the symptoms associated with their diabetes on the identity subscale did not significantly differ. Both adolescents and mothers believed that treatment could control their diabetes and both demonstrated good understanding about their knowledge of diabetes as demonstrated by high mean scores on the illness coherence subscale.

Illness Representations and demographic variables

There were no significant differences in illness representations for males and females. There was a positive relationship between duration of diabetes and the adolescent completed personal control dimension of the IPQ-R ($r=.429$, $p<.001$), indicating that adolescent participants who had had diabetes for longer were more confident in their ability to control the symptoms of their diabetes. Consistent with this, personal control, was negatively correlated with the age of the young person at diagnosis ($r=-.533$, $p<.001$), suggesting that participants diagnosed at an earlier age demonstrated strongly held beliefs that they can control the symptoms of their diabetes. Maternal beliefs about illness coherence were negatively correlated with the child's age at diagnosis ($r=-.533$, $p<.001$), meaning that mothers with children diagnosed at a younger age were more likely to endorse beliefs about their knowledge of the disease. Mothers' beliefs about illness coherence were positively correlated with duration of diabetes ($r=.460$, $p<.004$). This indicates that mothers of children who have had diabetes for a longer period of time believe that they have a good personal understanding and knowledge of the condition.

Illness Representations and measures of adherence, psychological morbidity, self-care and self-efficacy.

Adolescent beliefs about the emotional impact their diabetes has on them were found to be correlated with anxiety ($r=.412$, $p<.01$). There was no significant correlation between depression scores and adolescent beliefs about the emotional impact of diabetes ($r=.618$, $p>.05$). Maternal illness beliefs were not correlated with adolescent psychological morbidity.

There was no relationship between maternal or adolescent illness beliefs and measures of adherence, self-care or self-efficacy.

Difference scores between maternal and adolescent illness representations.

Table 5 gives details of the ‘similar’ and ‘dissimilar’ mother and adolescent groups with respect to illness representations.

*** Insert Table 5 ***

A significant difference was found between groups for the illness coherence subscale in terms of adolescent anxiety. Dissimilarity of beliefs about illness coherence, that is personal understanding of the illness, was associated with higher levels of adolescent anxiety ($F(1,35) = 4.905$, $p < .05$), but not depression ($F(1,35) = 3.60$, $p > .05$). There were no significant differences between the two groups in terms of adherence or self-efficacy.

Discussion

The aims of this study were two-fold, to explore if adolescent and maternal illness beliefs of diabetes are significantly different and if so, to establish if such incongruity is related to outcomes among adolescents. The hypothesis was that incongruity of adolescent and maternal illness beliefs of diabetes would be associated with poor self-management, low self-efficacy, poor well-being and poor adherence. These will be addressed in turn.

Aim - To establish if there are significant differences between maternal and adolescent illness representations of Type 1 diabetes.

The results demonstrated that maternal and adolescent illness beliefs of diabetes are significantly different on the majority of dimensions measured by the IPQ-R. Mothers view their child's diabetes as having more serious consequences and a higher emotional impact on their child than the children themselves. These findings are consistent with the study by Law (19). Significant differences between maternal and adolescent beliefs were also found for the timeline dimension whereby mothers believed that diabetes was more chronic and recurring in nature than their children. Furthermore, maternal and adolescent beliefs about the adolescent's personal control of diabetes were found to be significantly different with maternal participants believing their child to have greater personal control over diabetes than their child thinks they have.

Although there is no simple explanation for the differences observed in maternal and adolescent beliefs, the framework of the SRM may help to identify potential mitigating factors. It is possible that differences observed in illness beliefs between

mother and child are at least partially attributable to different pools of general information that have been assimilated from previous social communications and cultural knowledge of the illness. This is identified in the SRM as the first source of information on which people base their illness representations (15). As such, due to their age, adolescents have more limited information to inform their beliefs in comparison to their mothers who may have accrued a greater amount of knowledge over a longer period.

The SRM proposes that the second source of information on which people base their illness beliefs is information from significant others, such as parents and doctors (15). The current study only addressed the illness representations of the adolescent and mother. It may be that illness beliefs of fathers, siblings, peers and medical staff are important factors which influence the development of illness beliefs.

The third source of information identified by the SRM on which people construct illness beliefs is the current and past experience of the illness (15). A carer's indirect experience of an illness will clearly differ from that of the direct experience of the individual who is suffering it. Furthermore, this study found that diagnosis at a younger age and therefore a longer duration of disease was associated with adolescent beliefs about high levels of personal control over the illness. This finding has not been reported elsewhere in the literature (see Chapter 2). This relationship was also seen in the mothers; mothers of adolescents with longer duration and earlier age at diagnosis positively endorsed beliefs about their understanding of the disease. This suggests that information derived from past experience of the illness can inform illness beliefs. A further reflection of this is that HbA1c was significantly correlated with the age of the

adolescent at diagnosis with those diagnosed later demonstrating poorer glycaemic control. Again this may reflect knowledge accrued over time that diabetes can be effectively controlled. In the context of the SRM these findings make sense taking into account the role of expanding knowledge and changing personal experience and illness beliefs. Alternatively, there may be other factors which contribute to poorer glycaemic control in those diagnosed with Type 1 diabetes during adolescence rather than childhood.

Aim - To explore the relationship between similarity of adolescent and maternal illness representations and self-management, self-efficacy, adherence and well-being in adolescents with diabetes.

This study found that incongruity between maternal and adolescent illness representations were evident for the illness coherence domain of the IPQ-R and was related to adolescent anxiety, with adolescents having higher levels of anxiety in the 'incongruent' group. Thus, the hypothesis that incongruity in illness representations between mother and child would have a negative impact on adolescent psychological well-being was upheld. This finding is consistent with the findings of Salewski and colleagues, (18) and Richards and colleagues (17) who reported significant relationships between incongruity of illness beliefs and psychological well-being.

Hypothesis - Significant differences between maternal and adolescent illness representations of diabetes will be associated with 1) poor self- management, 2) low self-efficacy, 3) poor psychological well-being and (4) poor adherence in the adolescent with Type 1 diabetes.

Contrary to the hypothesis, no effect of ‘incongruity’ was found with regard to self-efficacy, adherence or self-management. However, HbA1c was significantly associated with anxiety indicating that poorer glycaemic control was related to higher levels of anxiety. Given this observed association it seems likely that identifying factors related to or contributing to adolescent anxiety would be important to help maintain good glycaemic control.

Study limitations

One limitation of the current study is the sample used. The sample was a convenience sample of adolescents attending out-patient appointments. Ethical approval did not allow for any information being collected about non-participants. This of course makes it unclear as to the overall representativeness of the sample and therefore the generalisability of these results.

In addition, it is fully acknowledged that multiple correlational analysis was conducted increasing the possibility of Type 1 errors being made, that is finding significant relationships by chance.

However, the strength in the findings of the current study lie in the pattern of results with predictable associations found between variables which have often been reported by previous research in this area.

Finally, given the cross-sectional nature of this study, conclusions about the causal role of illness representations cannot be made. To do so would require further exploration using a prospective, longitudinal study design.

Clinical and research implications

The current study identified that adolescents and their mothers can hold significantly different beliefs about Type 1 diabetes. Importantly, incongruity of beliefs was found to be related to adolescent anxiety. Given the importance of illness beliefs, including these factors in the clinical assessment of adolescents with Type 1 diabetes may prove helpful, particularly in cases where there is evidence of difficulties in maintaining good glycaemic control or problems in associated areas such as self-care or psychological morbidity. The assessment and exploration of illness beliefs may allow for the identification of specific areas of concern which then may be amenable to cognitive type strategies to help modify and challenge beliefs.

Given the importance of the social context of illness beliefs, work with young people and their mothers in a clinical setting could usefully be informed by this. Exploration of the shared understanding between the mother and adolescent of Type 1 diabetes could not only highlight areas of discrepancy or consistency, but also open up discussion between them about the experience of diabetes for each of them. The hope would be that this would nurture greater understanding between mother and adolescent, setting the foundations for developing shared goals and collaborative strategies to help the young person control their own diabetes with the support and understanding of their family.

The current study is only one of two studies which look specifically at the illness representations of adolescents with Type 1 diabetes and those of their mothers. More research is needed in this area to further explore illness representations of Type 1 diabetes. In addition to maternal illness beliefs, research could usefully focus on paternal illness beliefs and those of significant others such as siblings or peers.

Methodologically, both studies have relied on cross-sectional data however a longitudinal study would allow for the causal role of illness beliefs to be explored. It would also be of theoretical interest to see how illness beliefs of young people change over time and investigate what factors are associated with change. Future research could also usefully assess further the importance of the age of the child at diagnosis for subsequent illness beliefs of adolescents and mothers.

Conclusions

This study addressed the relationship between adolescent and maternal illness representations of Type 1 diabetes and their associations with adherence, self-management, self-efficacy and psychological morbidity. It provides further evidence to support the findings of existing studies; illness representations between adolescent and mother can be significantly different and incongruity or a lack of shared illness representation between mother and adolescent can be detrimental to psychological well-being. It is hoped that future research will explore these relationships further and in addition may usefully develop clinical interventions to help identify such beliefs that may then be amenable to cognitive techniques.

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Table 1: Adolescent participants: demographics and physiological indices of adherence

Characteristic	Mean (n=41)*	SD	Range
Demographics			
Age	13.03	.891	12-15
Age at diagnosis	8.03	3.41	.9-12.6
Duration of diabetes	4.94	3.43	1-12.4
Gender	Male 18	Female 23	
Physiological adherence			
HbA1c	8.78 (38)*	1.07	6.8-11.2
Glucose meter 14 day mean	11.34 (25)*	2.64	6.6-17.7
Glucose meter frequency of testing	29.88 (25)*	20.5	0-66

* denotes number of participants mean value is derived from

Table 2: Adolescent psychological morbidity, self-efficacy and self-reported adherence measures

Characteristic		Mean	n	SD	Range (observed)
Psychological morbidity					
HADS	Anxiety	4.67	(39)	3.97	0-14
	Depression	2.03	(39)	2.70	0-14
Self-efficacy					
VAS	BG monitoring*	9.18	(41)	2.17	0-10
	Insulin admin.	8.95	(41)	2.15	0-10
	Diet	8.17	(41)	1.83	3.5-10
	Exercise	8.45	(41)	2.25	1.5-10
Self-reported adherence					
SDSCA	Diet	66.51	(40)	13.46	31-94
	Exercise	50	(40)	24.35	12.5-100
	BG monitoring*	83.97	(39)	19.64	83.97-100
	Insulin admin.	98.72	(39)	98.71	75-100

*Blood Glucose monitoring

Table 3: Adolescent and maternal illness representations

Illness representation	Adolescent (n=41) Mean (SD)	Maternal (n=40) Mean (SD)	p: two-tailed (n=40)
Identity	4.80 (2.63)*	5.41 (3.32)*	ns‡
Timeline (chronicity)	4.11 (0.61) †	4.61 (0.48) †	p<.001‡
Consequences	2.57 (0.55) †	3.24 (0.78) †	p<.001
Personal	4.06 (0.53) †	4.39 (0.59) †	p<.01
Treatment	3.48 (0.63) †	3.53 (0.79) †	ns
Illness Coherence	4.07 (0.75) †	4.23 (0.70) †	ns‡
Timeline cyclical	2.67 (0.84) †	3.31 (0.93) †	p<.01
Emotional representations	2.72 (0.74) †	3.86 (0.60) †	p<.001‡

*Total mean score

†Adjusted mean score (sum of scale items divided by number of items)

‡Wilcoxon ranked test. All others paired samples t-tests.

Table 4: Per cent of adolescent and maternal participants endorsing causative factors of diabetes

	Adolescent (n=41) Mean (SD)	% endorsing	Maternal (n=40) Mean (SD)	% endorsing
Chance/bad luck	2.73 (1.51)	39.0	2.58 (1.53)	30.0
Hereditary	2.56 (1.34)	34.2	2.73 (1.41)	37.5
Altered immunity	2.41 (1.32)	24.4	2.98 (1.48)	40.0
Diet/eating habits	2.12 (1.24)	21.9	1.54 (0.94)	5.2
Germ/virus	2.20 (1.16)	17.1	3.38 (1.31)	55.0

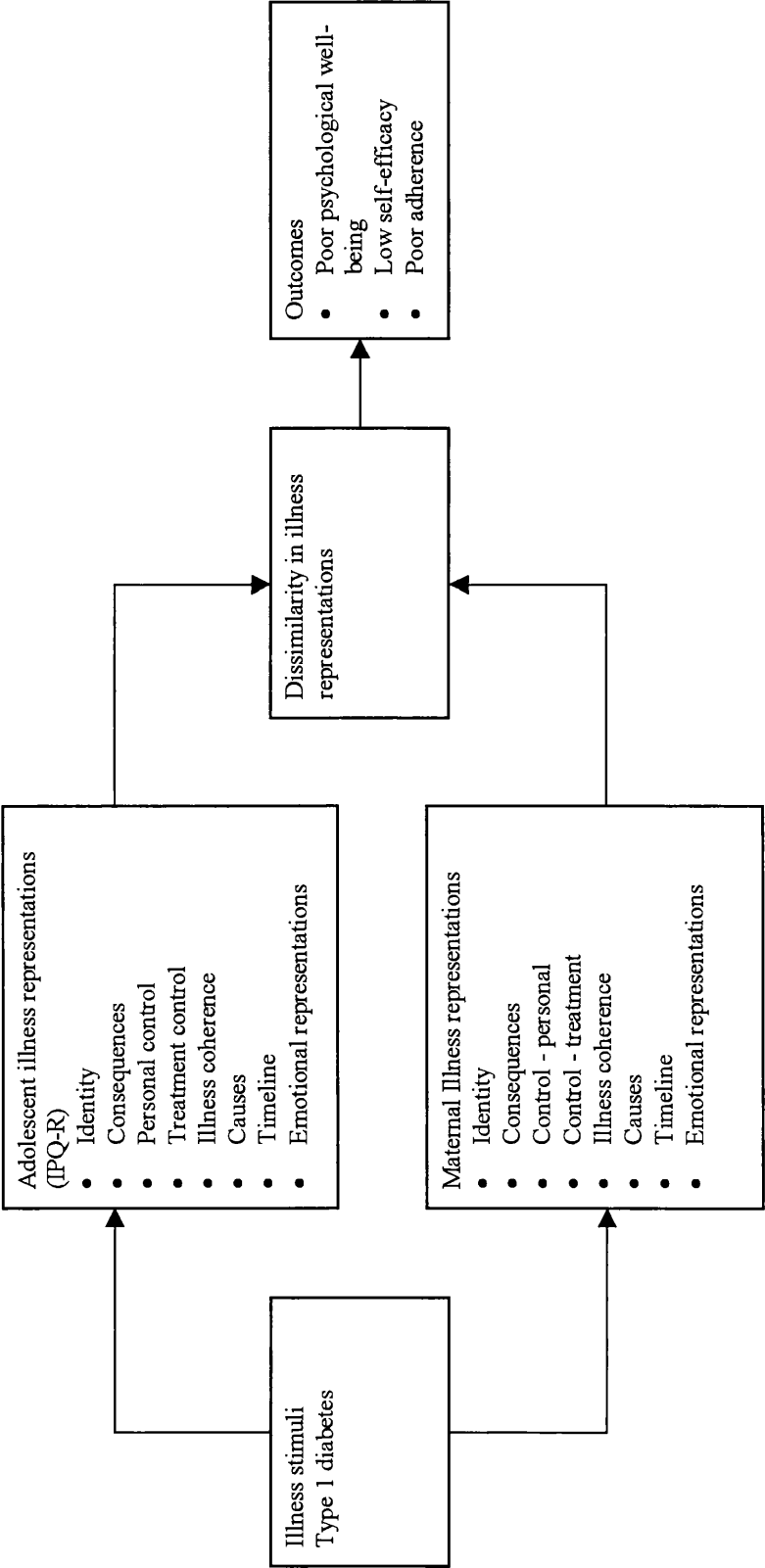
Table 5: Similarity and dissimilarity of illness representations

Illness representation	Range	Mean (SD)	'Similar'* (n)	'Dissimilar' * (n)
Timeline (chronicity)	-2.00 – 1.33	.506 (.626)	34	7
Consequences	-2.78 – 1.44	.702 (.790)	33	8
Personal	-2.17 – 2.00	.328 (.763)	31	10
Treatment	-2.00 – 1.60	.155 (.855)	27	14
Cyclical	-3.25 – 2.25	.653 (1.199)	30	11
Illness Coherence	-2.80 – 1.80	.133 (1.005)	30	11
Emotional representations	-2.80 – 0.25	-1.14 (.846)	25	16
Total **	-1.53 – 0.15	.516 (.396)	30	11

* Similar scores =/ < 1SD of mean; Dissimilar scores > 1SD of mean

**Total mean similarity scores for all subscales

Figure 1: Common-sense model of dissimilarity in Type 1 diabetes: illness beliefs held by mothers and adolescents. (Adapted from Richards and colleagues p50 (17))



Chapter 5: Single Case Research Study Proposal

Can teaching a simple visual imagery technique enhance recall of verbally presented word pairs in a 12 year old boy with a verbal working memory deficit following resection of right frontal tissue for intractable epilepsy?

Kirsten Kernohan

Supervisor: Dr Sarah Wilson

July 2007

Word count: 4131 (including abstract)

Abstract

Epilepsy is a relatively common, chronic, medical condition characterised by a predisposition to recurrent seizures. The main treatment is by anti-convulsant medication. In some instances, epilepsy is resistant to medication, and surgery, involving cortical resection of abnormal tissue, is recommended. There is no characteristic neuropsychological profile for people who have epilepsy or those who have had surgery, however, memory problems are frequently reported. There is also little evidence for the efficacy of cognitive rehabilitation in children presenting with memory problems. However, the limited evidence available suggests that visual imagery may be an effective compensatory strategy for those presenting with verbal memory impairments.

This proposed study aims to evaluate the effectiveness of a simple visual imagery strategy and its application to memory for verbal material. A single case method would be used in the cognitive rehabilitation of a 12 year old boy, 18 months following resection of abnormal tissue, in the right frontal lobe, as a result of intractable complex partial epilepsy. The intervention involves teaching the subject a simple visual imagery technique to use when presented with verbal material. Specific examples of everyday situations will be identified, with the subject and his mother, to encourage the generalisability of the visual imagery strategy out with the clinical setting. Methodological and ethical considerations are discussed. It is hypothesised that the use of visual imagery will enhance memory for verbal material.

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Appendix 1.1 – Clinical Psychology instructions to authors

Submitting to *Clinical Psychology*

- Articles of 1000-2000 words are welcomed. Send two copies of your contribution.
- When sending hard copy, make sure it is double spaced, in a reasonably sized font and that all pages are numbered.
- Give a 40-word summary at the beginning of the paper.
- Contributors are asked to use language which is psychologically descriptive rather than medical and to avoid using devaluing terminology; i.e. avoid clustering terminology like “the elderly” or medical jargon like “person with schizophrenia”. If you find yourself using quotation marks around words of dubious meaning, please use a different word.
- Articles submitted to *Clinical Psychology* will be sent to members of the Editorial Collective for refereeing. They will then communicate directly with authors.
- We reserve the right to shorten, amend and hold back copy if needed.
- Include a word count at the end (including references).
- Spell out all acronyms the first time they appear.
- Include the first names of all authors and give their employers, and remember to give a full postal address for correspondence.
- Give references in *Clinical Psychology* style, and if a reference is cited in the text make sure it is in the list at the end.
- Don't include tables and figures unless they save space or add to the article.
- Ask readers to request a copy of your questionnaire from you rather than include the whole of it in the article.

Appendix 2.1 – Instructions for authors British Journal of Health Psychology

Notes for Contributors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy and reviewing

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at <http://bjhp.edmgr.com>.

First-time users: Click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: Click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

- Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - A title page template is available to download.
- Abstract
- Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - Editorial Manager - Tutorial for Authors
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions - British Journal of Health Psychology - Structured Abstracts Information
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (<http://www.apastyle.org>).

6. Publication ethics

Code of Conduct - Code of Conduct, Ethical Principles and Guidelines
Principles of Publishing - Principles of Publishing

7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication for easy and cost-effective dissemination to colleagues.

9. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

10. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymised)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- Tables, figures, captions placed at the end of the article or attached as separate files.

Appendix 2.2: Data Extraction Tables

	Edgar & Skinner (2003)	Law et al. (2002)	Griva, Myers & Newman (2000)	Law (2002)
Study topic	IR's, coping and well-being	IR's, SM, well-being	Illness representations & self-efficacy	M & A IR's well-being
AIMS				
Aim reported?	1	1	1	1
Hypotheses clearly stated?	0	1	1	0
SAMPLING PROCEDURE				
Sample size reported?	1	1	1	1
States where recruited from?	1	1	1	1
Incl' criteria adequately described?	1	1	1	1
Excl' criteria adequately described?	1	1	1	1
Sample representative? (Clinic=0)	0	0	1	0
Are initial refusal rates reported?	1	1	1	1
Follow up drop out rates reported?	N/A	N/A	N/A	N/A
Analysis re: participators/dropouts?	0	0	1	0
Ethical issues adequately addressed?	1	0	1	1
DEMOGRAPHIC DETAILS				
Mean and SD of age described?	1	1	1	1
Age range or median age described?	1	1	1	1
Male: Female ratio described?	1	1	1	1
CLINICAL CHARACTERISTICS				
Duration of diabetes?	1	1	1	1
Age at onset?	1	0	0	0
Duration of study?	1	0	1	1
ASSESSMENT				
Measure of illness representations?	1	1	1	1
Outcome measures?	1	1	1	1
Are measures used well described?	1	1	1	1
Direct administration initially?	1	0	1	0
Direct administration at f/up?	N/A	N/A	N/A	N/A
Measures reliable and valid?	1	1	1	1
ANALYSIS / INTERPRETATION				
Was a power analysis done?	0	0	0	0
Are means included?	1	1	1	1
Are standard deviations included?	1	1	1	1
Statistics appropriate for the study?	1	0	1	1
Are the results clearly stated?	1	1	1	1
Generalisability discussed?	1	1	1	1
Total Score (%)	23 (79%)	19 (65%)	25 (86%)	21 (72%)
Rating	High	Moderate	High	Moderate

Appendix 2.2: Data Extraction Tables

	Skinner & Hampson (1998)	SM,	Skinner, John & Hampson (2000)	Skinner & Hampson (2001)
Study topic	IR'S, well-being, social support		IR's &social support predict self-care and well-being?	IR's &social support predict self-care and well-being?
AIMS				
Aim reported?	1		1	1
Hypotheses clearly stated?	1		1	1
SAMPLING PROCEDURE				
Sample size reported?	1		1	1
States where recruited from?	1		1	1
Incl' criteria adequately described?	1		1	1
Excl' criteria adequately described?	0		0	1
Sample representative? (Clinic=0)	0		0	0
Are initial refusal rates reported?	1		0	1
Follow up drop out rates reported?	N/A		1	1
Analysis re: participators/dropouts?	1		1	1
Ethical issues adequately addressed?	1		0	1
DEMOGRAPHIC DETAILS				
Mean and SD of age described?	1		1	1
Age range or median age described?	1		1	1
Male: Female ratio described?	1		1	1
CLINICAL CHARACTERISTICS				
Duration of diabetes?	1		1	1
Age at onset?	0		0	0
Duration of study?	1		1	1
ASSESSMENT				
Measure of illness representations?	1		1	1
Outcome measures?	1		1	1
Are measures used well described?	1		1	1
Direct administration initially?	0		0	0
Direct administration at f/up?	N/A		0	0
Measures reliable and valid?	1		1	1
ANALYSIS / INTERPRETATION				
Was a power analysis done?	0		0	0
Are means included?	1		1	1
Are standard deviations included?	1		1	1
Statistics appropriate for the study?	1		1	1
Are the results clearly stated?	1		1	1
Generalisability discussed?	1		1	1
Total Score (%)	22 (75%)		22 (75%)	24 (83%)
Rating	High		High	High

Appendix 2.2: Data Extraction Tables

	Skinner et al. (2003) study 1	Skinner et al. (2003) study 3	Skinner et al. (2003) study 4
Study topic	Develp't of DIRQ	Develp't of DIRQ	Develp't of DIRQ
AIMS			
Aim reported?	1	1	1
Hypotheses clearly stated?	1	1	1
SAMPLING PROCEDURE			
Sample size reported?	1	1	1
States where recruited from?	1	1	1
Incl' criteria adequately described?	0	0	0
Excl' criteria adequately described?	0	0	0
Sample representative? (Clinic=0)	0	0	0
Are initial refusal rates reported?	1	1	1
Follow up drop out rates reported?	n/a	n/a	n/a
Analysis re: participators/dropouts?	0	0	0
Ethical issues adequately addressed?	1	1	1
DEMOGRAPHIC DETAILS			
Mean and SD of age described?	1	1	1
Age range or median age described?	1	1	1
Male: Female ratio described?	1	1	1
CLINICAL CHARACTERISTICS			
Duration of diabetes?	1	1	1
Age at onset?	0	0	0
Duration of study?	0	0	0
ASSESSMENT			
Measure of illness representations?	1	1	1
Outcome measures?	1	1	1
Are measures used well described?	1	1	1
Direct administration initially?	0	0	0
Direct administration at f/up?	n/a	n/a	n/a
Measures reliable and valid?	1	1	1
ANALYSIS / INTERPRETATION			
Was a power analysis done?	0	0	0
Are means included?	1	1	1
Are standard deviations included?	1	1	1
Statistics appropriate for the study?	1	1	1
Are the results clearly stated?	1	1	1
Generalisability discussed?	n/a	n/a	n/a
Total Score (%)	18(62%)	18 (62%)	18 (62%)
Rating	Moderate	Moderate	Moderate



4/05/05

Version 1

Participant Information Sheet – Adolescent Group

Project Title: Similarity of adolescent and maternal illness beliefs about Type 1 diabetes and its relationship to well-being, self-efficacy and adherence to treatment?

You are being invited to take part in a research study. Before you decide if you wish to take part it is important to read the following information so you understand why the research is being done and what it will involve. Please take the time to read the information carefully and decide if you wish to take part.

What is the purpose of the study?

People have their own beliefs about their diabetes. For example about what causes it and how long it will last for. It has been found that these beliefs are related to issues such as sticking to the diet that is recommended for people who have diabetes. Little is known about how these beliefs develop and if they are similar or different from the beliefs held by the young person's mother. The aim of this study is to see if the beliefs of young people with Type 1 diabetes are similar or different to the beliefs of their mothers' about diabetes.

It is hoped that this study will develop our understanding of similarities of beliefs about diabetes between young people and their mothers and how these relate to well being, management of diabetes and adherence to treatment. Understanding this area may help us develop better interventions to help with young people experiencing difficulties in these areas.

Why have I been chosen?

You have been chosen because you have Type 1 diabetes, diagnosed more than 1 year ago. Also you are aged 12-15 years and attend the diabetes out-patient service at Yorkhill. All together 30 young people and their mothers will be studied in this project.

Do I have to take part?

No. You do not have to take part if you do not wish to do so. If you do decide to take part you will be asked to keep this information sheet and you and your mother will be asked to sign a consent form. If you do decide to take part you can withdraw or stop taking part at any time and you do not need to give a reason for this. If you decide not to take part or to stop taking part then this will not change the care you receive. Any information that had been collected from you would then be destroyed.

What would I have to do?

If you decide that you would like to take part in the study then I would meet with you and your mother at your usual out patient appointment. You would be asked to complete 4 questionnaires. The first questionnaire asks you about your diabetes. The second questionnaire asks about how you have been feeling over the past week. The third questionnaire asks you about how confident you feel about managing your diabetes for example doing your blood glucose checks. The fourth and final questionnaire asks about how often you do the activities you have been advised to do for example how often you stick to the diet advice or how often you do your insulin injections. You will also be asked if you have had any hypos in the past 4 weeks. The questionnaires should take about 30 minutes to complete. If you have your blood glucose monitor with you the results from the past week will be recorded. The result of your blood test (HbA1c) will be recorded.

If you do decide to take part in the study I will only need to meet with you and your mother for this one occasion at your usual appointment time. If you are in a hurry then you will be able to complete the questionnaire at home, you will be given a stamped addressed envelope to return your questionnaire, or if you have time at clinic you can complete them in a clinic room in the out patient department.

What are the possible disadvantages of taking part?

It may be that thinking about your diabetes and how you are feeling may make you feel a little sad or upset. If this was to be the case then this could be discussed with you when we meet. If you were having difficulties then with you and your mother's permission this could be discussed with a member of the diabetes team or with your GP.

What are the possible advantages of taking part?

Although there will be no immediate benefits for you it is hoped that greater understanding of the beliefs held by young people and their mothers may help with interventions in the future. A benefit may be that after you and your mother have filled out the questionnaire you may wish to speak with each other about your diabetes.

Will my taking part in the study be kept confidential?

All information collected about you during the study will be kept strictly confidential. A copy of the consent form will be kept in your medical notes. Any information collected from you for example the questionnaires you complete will not have your name or personal information on them so that you cannot be recognised from them. However a member of the diabetes team or your GP would be contacted if the researcher was concerned that your questionnaire revealed something that the diabetes team or your G.P should know about for example if you were feeling very upset and worried. Every attempt would be made to discuss this with you first.

What will happen to the results of the research study?

Results will be used as part of the main researcher's Doctorate in Clinical Psychology, and will be submitted for publication in a scientific journal. This can take around two to three years. In addition a summary of the results of the study will be sent to participants if they would like this. You will not be identified in any report or publication.

Who can I contact if I want more information?

If you wish to discuss any points covered in the information sheet, or wish to ask any questions about the study please do not hesitate to contact **Kirsten Kernohan** at the address or telephone number given below. I will be happy to answer any questions you may have.

Kirsten Kernohan
Trainee Clinical Psychologist
Division of Community Based Sciences
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 0607

You can also contact me any time during the duration of the study. Alternatively you can also contact **Dr Sarah Wilson** at the address and telephone number given below.

Dr Sarah Wilson
Health Psychologist
Division of Community Based Sciences
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 3920

Thank- you for reading this information



4/05/05

Version 1

Participant Information Sheet – Maternal Group

Project Title: Similarity of adolescent and maternal illness beliefs about Type 1 diabetes and its relationship to well-being, self-efficacy and adherence to treatment?

You are being invited to take part in a research study. Before you decide if you wish to take part it is important to read the following information so you understand why the research is being done and what it will involve. Please take the time to read the information carefully and decide if you wish to take part.

What is the purpose of the study?

People have their own beliefs about their diabetes. For example about what causes it and how long it will last for. It has been found that these beliefs are related to issues such as sticking to the diet that is recommended for people who have diabetes. Little is known about how these beliefs develop and if they are similar or different from the beliefs held by the young person's mother. The aim of this study is to see if the beliefs of young people with Type 1 diabetes are similar or different to the beliefs of their mothers' about diabetes.

It is hoped that this study will develop our understanding of similarities of beliefs about diabetes between young people and their mothers and how these relate to well being, management of diabetes and adherence to treatment. Understanding this area may help us develop better interventions to help with young people experiencing difficulties in these areas.

Why have I been chosen?

You have been chosen because you are the mother of a young person with Type 1 diabetes, diagnosed more than 1 year ago. All together 30 young people and their mothers will be studied in this project.

Do I have to take part?

No. You do not have to take part if you do not wish to do so. If you do decide to take part you will be asked to keep this information sheet and you will be asked to sign a consent form on behalf of your child and also for your own participation. If you do decide to take part you can withdraw or stop taking part at any time and you do not need to give a reason for this. If you decide not to take part or to stop taking part then this will not change the care your child receives. Any information that had been collected from you would then be destroyed.

What would I have to do?

If you decide that you would like to take part in the study then I would meet with you and your child at your usual out patient appointment. You would be asked to complete 1 questionnaire. This questionnaire asks about your son/daughter's diabetes.

If you do decide to take part in the study I will only need to meet with you and your child for this one occasion at their usual appointment time. If you are in a hurry then you will be able to complete the questionnaire at home and you will be given a stamped addressed envelope to return your questionnaires, or if you have time at clinic you can complete the questionnaire in a clinic room in the out patient department.

What are the possible disadvantages of taking part?

It may be that thinking about your child's diabetes may make you feel mildly upset or worried. If this was to be the case then this could be discussed during the meeting.

What are the possible advantages of taking part?

Although there will be no immediate benefits for your child it is hoped that greater understanding of the beliefs held by young people and their mothers may help with interventions in the future. A benefit may be that after you and your child have filled out the questionnaire you may wish to speak with each other about your diabetes.

Will my taking part in the study be kept confidential?

All information collected about you and your child during the study will be kept strictly confidential. A copy of the consent form will be kept in your child's medical notes. Any information collected from you and your child for example the questionnaires you complete will not have your name or personal information on them so that you or your child cannot be recognised from them. However a member of the diabetes team or your GP would be contacted if the researcher was concerned that your child's questionnaire revealed something that the diabetes team or their G.P should know about for example if they were feeling very upset and worried. Every attempt would be made to discuss this with you first.

What will happen to the results of the research study?

Results will be used as part of the main researcher's Doctorate in Clinical Psychology, and will be submitted for publication in a scientific journal. This can take around two to three years. In addition a summary of the results of the study will be sent to participants if they would like this. You or your child will not be identified in any report or publication.

Who can I contact if I want more information?

If you wish to discuss any points covered in the information sheet, or wish to ask any questions about the study please do not hesitate to contact **Kirsten Kernohan** at the address or telephone number given below. I will be happy to answer any questions you may have.

Kirsten Kernohan
Trainee Clinical Psychologist

**Division of Community Based Sciences
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 0607**

You can also contact me any time during the duration of the study. Alternatively you can also contact **Dr Sarah Wilson** at the address and telephone number given below.

**Dr Sarah Wilson
Health Psychologist
Division of Community Based Sciences
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 3920**

Thank- you for reading this information

Appendix 3.3 – Consent form – adolescent participants



Study Number:

Patient Identification Number:

CONSENT FORM

Title of Project: Similarity of adolescent and maternal illness beliefs about Type 1 diabetes and its relationship to well being, self-efficacy and adherence to treatment.

Name of Researcher: Kirsten Kernohan

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected and all the data relating to my participation will be destroyed. ☐
3. I agree to take part in the above study. ☐

<hr/>	<hr/>	<hr/>
Name of Participant	Date	Signature

<hr/>	<hr/>	<hr/>
Name of Parent / Guardian	Date	Signature

<hr/>	<hr/>	<hr/>
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

Appendix 3.4 – Consent form – maternal participants



Study Number:

Patient Identification Number:

CONSENT FORM

Title of Project: Similarity of adolescent and maternal illness beliefs about Type 1 diabetes and its relationship to well being, self-efficacy and adherence to treatment.

Name of Researcher: Kirsten Kernohan

Please initial box

1. I confirm that I have read and understand the information sheet dated
(version) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and all the data relating to my participation will be destroyed. ☐
3. I agree to take part in the above study. ☐

<hr/>	<hr/>	<hr/>
Name of Participant	Date	Signature

<hr/>	<hr/>	<hr/>
Researcher	Signature	Date

1 for patient; 1 for researcher; 1 to be kept with hospital notes

MATERNAL PARTICIPANT CONSENT FORM VERSION 1.0 12.05.2005

Diabetes Care Instructions for Authors, Page 1

Last updated on 11 October 2006.

ABOUT THE JOURNAL

Diabetes Care is a journal for the health care practitioner that is intended to increase knowledge, stimulate research, and promote better management of people with diabetes. To achieve these goals, the journal publishes Original Articles on human studies in the following five categories: 1) Clinical Care/Education/Nutrition, 2) Epidemiology/Health Services/Psychosocial Research, 3) Emerging Treatments and Technologies, 4) Pathophysiology/Complications, and 5) Cardiovascular and Metabolic Risk. The journal also publishes clinically relevant Review Articles, Letters to the Editor, Brief Reports, and health/medical news or points of view. Topics covered are of interest to clinically oriented physicians, researchers, epidemiologists, psychologists, diabetes educators, and other health professionals. The journal does not publish descriptions of study designs without data or papers on *in vitro* studies.

POLICIES

All human investigation must be conducted according to the principles expressed in the Declaration of Helsinki. All studies involving animals must state that guidelines for the use and care of laboratory animals of the authors' institution or the National Research Council or any national law were followed.

Diabetes Care publishes only material that has not been published previously (either in print or electronically) and is not under consideration for publication elsewhere, with the exception of an abstract that is less than 400 words in length. Prior presentation of data (e.g., at a scientific meeting or via webcast) does not preclude publication in *Diabetes Care*, but should be disclosed in the Acknowledgments of the paper and in the author's comments to the editor upon manuscript submission.

All contributions, including solicited articles and symposia, are critically reviewed by the editors and invited referees. Reviewers' comments are usually provided to the authors. The decision of the editors is final.

As of 25 May 2005, ADA has modified its permission policies related to **reuse** and **post-prints**. Please see the Forms and Requirements section for the revised policy and the **statement of provenance** and other conditions.

Clinical Trials: As of 1 January 2006, all clinical trials submitted to *Diabetes Care* for consideration of publication must be registered (no matter when conducted). The International Committee of Medical Journal Editors (ICMJE) defines a clinical trial as "any research project that prospectively assigns human subjects to intervention or comparison groups to study the cause-and-effect relationship between a medical intervention and a health outcome. Studies designed for other purposes, such as to study pharmacokinetics or major toxicity (e.g., phase I trials), are exempt."

For definitions and further information, please see the section titled Obligation to Register Clinical Trials found in ICMJE's Uniform Requirements for Manuscripts Submitted to Biomedical Journals. Please note, however, that unlike ICMJE, ADA does not require trials to be registered before enrollment begins, although *Diabetes Care* does encourage this practice. When submitting your manuscript, please include

the unique trial number and the name of the registry (e.g., ClinicalTrials.gov or ISRCTN) at the end of the abstract and in your cover letter.

Registries must be approved by the ICJME. To date the approved registries are: "ClinicalTrials.gov", "www.ISRCTN.org", "www.actr.org.au", "www.umin.ac.jp", "www.trialregister.nl"

Prepublication. Beginning January 1, 2007, peer-accepted Original Articles and Brief Reports will be published ahead of print on the *Diabetes Care* Web site, within two weeks after acceptance, in unedited form. Before submitting an Original Article or Brief Report, please carefully review the entire manuscript. In particular, make sure to list full and correct names of all authors, include correct institutional affiliations for each author, and include all figures, legends, and tables within the uploaded document. Figures may appear within the text itself or at the end of the manuscript. A prepublished article subsequently goes through the normal production process, which includes copyediting, composition, and proofreading, and will be published in its final form in the first available print and online issue of *Diabetes Care*.

When citing the prepublished version of your article, please use the DOI (digital object identifier) in place of volume, page range, and year (see below for an example). The DOI of your article will begin with 10.2337, followed by the article number assigned when you submitted your article via the online manuscript submission system (e.g., 10.2337/dc06-9999).

Example: Kohler C, Norton N, Farber K, Briggs E: How to cite a prepublished article in ADA journals. *Diabetes Care* 10.2337/dc06-9999

The editor-in-chief of *Diabetes Care*, Vivian Fonseca, MD, FRCP, began his term with the January 2007 issue. Dr. Fonseca's editorial team began reviewing first submissions on July 1, 2006.

Editorial Note: Due to an increasing number of submissions and limited editorial space, manuscripts will initially be reviewed by an editorial committee and/or the editor. Manuscripts that exceed the word limit will be automatically declined, and only those that meet a priority score above the 50th percentile will be reviewed.

EDITORIAL OFFICE CONTACT INFORMATION

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6925	E.	Tenth	St.
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phone: (703)	549-1500,	ext. 1775	fax: (317) 354-8379
e-mail: DiabetesCare@diabetes.org			

FORMS AND REQUIREMENTS

All authors must sign the manuscript submission form. As of 1 January 2006, the manuscript submission form replaces the previously required Copyright Assignment Agreement and Duality of Interest Disclosure forms. The new single-page form addresses ADA's policies on 1) originality and authorship, 2) copyright assignment, and 3) potential conflict of interest. Each author must read the three sections, check the appropriate boxes, and sign the document where indicated (all authors must sign and print their names; attach additional pages if necessary).

The corresponding author must fax (317/354-8379) or mail the completed form for all authors to the Editorial Office when the manuscript is submitted. Your submission will not be considered complete until the form has been received. Please write your manuscript number, which is assigned once you have finished the online submission process, where indicated on the manuscript submission form.

Statement of Originality and Authorship

Diabetes Care subscribes to the requirements stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals that authorship implies substantial contributions to conception and design or analysis and interpretation of data and drafting of the article or critical revision for important intellectual content. The editor reserves the right to query authorship contribution. *Diabetes Care* limits the number of authors to 8 from the same institution and 12 from multiple institutions.

Copyright Assignment

The American Diabetes Association (ADA) holds the copyright on all material appearing in *Diabetes Care*. All authors must check the appropriate boxes and sign the manuscript submission form, which transfers copyright to the ADA in accordance with the Copyright Revision Act of 1976.

As of 25 May 2005, ADA's copyright assignment form has been modified to address permission policies related to **reuse** and **post-prints**. Please see the revised policy below for the **statement of provenance** and other conditions:

Reuse. Authors are permitted to reuse portions of their ADA-copyrighted work, including tables and figures, in their own work, and to reuse portions or all of their ADA-copyrighted work for educational purposes, without submitting a request to ADA, provided that the proper citation and copyright information is given.

Post-prints. Authors are permitted to submit the final, accepted version of their manuscript to their funding body, such as NIH, or institution for inclusion in their funding body or institution's database, archive, or repository, or to post the final, accepted version on their personal Web site. These manuscripts may be made freely accessible to the public upon acceptance, provided that the following conditions are observed:

1. Post-prints must include the following statement of provenance and, once the final version has been published in the journal, a link to the final published version of the paper on the journal's Web site: "This is an author-created, uncopyedited electronic version of an article accepted for publication in *Diabetes Care* (<http://care.diabetesjournals.org>). The American Diabetes Association (ADA), publisher of *Diabetes Care*, is not responsible for any errors or omissions in this version of the manuscript or any

version derived from it by third parties. The definitive publisher-authenticated version is available online at [URL]."

2. The version of the manuscript deposited or posted must be identical to the final accepted version, with the exception of the addition of the above statement and any changes necessary to correct errors. Authors may make changes to the posted version to correct mistakes or may issue an erratum at any time. However, the final published version of the manuscript may not be deposited, posted, or later substituted for the post-print.

Duality of Interest

All authors must read the ADA Policy Statement on Duality of Interest and check the appropriate box on the manuscript submission form, which can also be found in every issue of *Diabetes Care*. Any author who has duality of interest to disclose must attach an additional statement that explains the nature of the duality or conflict of interest. Relevant duality or conflict of interest (or lack thereof) should also be disclosed in the authors' comments to the editor during the submission process.

Color Figure Approval

If your manuscript is accepted for publication and contains color figures, the corresponding author must sign and return a color approval form. Forms will be faxed or e-mailed from the Editorial Office upon receipt of color figures. The cost of printing in color, to be borne by the author, is \$630 U.S. per color figure. Color fees are based on individual figures as a whole, not by the part, i.e., *A, B, C*, etc. After submission of the form, authors will receive a pro forma invoice for publication fees when page proofs become available.

MANUSCRIPT FORMAT

If you're interested in submitting an Original Article, Brief Report, Commentary, Review Article, or Letter to the Editor to Diabetes Care, the following section provides useful information on how to properly format your manuscript for submission. If you're interested in general information about these types of articles, please view the "About the Journal" page at <http://care.diabetesjournals.org/misc/about.shtml>.

Every manuscript, including Letters and Brief Reports, must have an accompanying **title page**. The title page should include the title (of course); a short running title (less than 47 characters and spaces); the first name, middle initial, last name, and the highest academic degree of each author; affiliation (in English) of each author during the study being reported; name, current address, telephone number, fax number, and e-mail address of the corresponding author; and the word count and number of tables and figures. (More information about calculating the word count can be found in the Submitting a Manuscript section.)

All text and tables should be saved in Word document format. Doing so will allow our Editorial Office to verify the word count and our production staff to turn your paper (if accepted) into an article.

Please do not use headers, footers, or endnotes in your paper.

Font: Text, including title & author names, should be in 12pt font, Arial or Times New Roman (Text in tables should be no smaller than 10pt font)

Margins: Margins should be 1" Top and Bottom, 1.25" on Left side and 1" on right side.

Section Headers: Sections should follow each other consecutively (except for Abstract) and not begin on a new page.

Original Articles

Original Articles should be arranged in the following order: title page, structured abstract (see below), introduction (no heading), "Research Design and Methods," Results," "Conclusions," "Acknowledgments," "References," tables, and figure legends.

A **structured abstract** is required for all Original Articles. The abstract for an Original Article should not exceed 250 words. (This is not to be confused with abstracts submitted to the Annual Scientific Meeting, for which the word limit is higher.) The abstract must be self-contained and clear without reference to the text and should be written for a general journal readership. The abstract format should include four sections: "Objective," the purpose or hypothesis of study; "Research Design and Methods," the basic design, setting, number of participants and selection criteria, treatment or intervention, and methods of assessment; "Results," significant data found; and "Conclusions," validity and clinical applicability.

The **word limit** for Original Articles is 5,000 words, allowing 500 words for each table or figure in the article. For example, an article with two figures and one table should contain no more than 3,500 words [5,000 - (3 x 500)]. All words should be counted except for tables, table legends, figure legends, and references. Include the title, author names, abstract, entire text, and acknowledgments in the word count. References are limited to three pages. Authors who cannot conform to this limit should provide specific reasons in their comments to the editor. Exceptions to the 5,000-word limit are rare.

In the case of **multicenter studies**, authors should provide a list of participating investigators as an appendix to the paper. Papers will not be reviewed if this information is not included.

Where appropriate, **clinical and epidemiological studies** should be analyzed to see if there is an effect of sex or ethnicity. If there is no effect, it should be so stated in the "Results" section.

Authors of reports of **randomized controlled trials** are required to use the instructions and checklist in the Consolidated Standards of Reporting Trials (CONSORT) Statement. The instructions and checklist are designed to ensure that information pertinent to the trial is included in the study report.

Please see the corresponding sections below for information on acknowledgments, references, tables, and figures.

Brief Reports

Brief Reports should be formatted in one of two ways:

- Clinical observations/research report style, which consists of a short introductory paragraph stating the study's objectives, followed by four concise sections: "Research Design and Methods," "Results," "Conclusions," and "References."
- Case report/case study style, which consists of a short introductory paragraph followed by four sections: "History and Examination," describing the patient and giving a brief history; "Investigation," discussing the treatment findings and results; "Conclusions," summarizing the importance of the findings/results in one or two paragraphs; and "References."

Neither format should exceed 1,000 words, excluding the references. Each Brief Report may include either one table or one figure, but not both. Each manuscript must include a title page stating the title, the short running title, the authors' full names and degrees, the authors' affiliations, the contact information for the corresponding author, the word count, and whether a table or figure is included.

Please see the corresponding sections below for information on acknowledgments, references, tables, and figures.

Manuscript Submission Tip: When submitting a Brief Report online, enter the short introductory paragraph in the "Abstract" field. This will allow you to continue through the submission process. For more information on uploading your manuscript, see the Submitting a Manuscript section.

Commentaries

Diabetes Care publishes Commentaries on an occasional basis. Commentaries are brief articles presenting the authors' views on a topic of current clinical interest. In general, Commentaries are invited by the editors.

Manuscript Submission Tip: To bypass the "Abstract" field when submitting a Commentary, type "None" in the "Abstract" field. For more information on uploading your manuscript, see the Submitting a Manuscript section.

Review Articles

The formatting requirements for Review Articles are similar to those for Original Articles. The word count should not exceed 5,000 words; each table and figure counts as 500 words. Instead of having a structured abstract, however, Review Articles should include an introductory paragraph. Please see the corresponding sections below for information on acknowledgments, references, tables, and figures.

Review Articles are usually taken by invitation. However, an invitation to submit does not guarantee publication. Like Original Articles, Review Articles are subject to peer review.

If you would like to submit an uninvited review, you must submit a proposal to the editors. Click here for information on submitting a proposal for a Review Article.

Manuscript Submission Tip: When submitting a Review Article online, enter the short introductory paragraph in the "Abstract" field. This will allow you to continue through the submission process. For more information on uploading your manuscript, see the Submitting a Manuscript section .

Letters to the Editor

Beginning with the January 2007 edition of *Diabetes Care*, Letters to the Editor will be published in the online version only of *Diabetes Care*. Therefore, any Letter to the Editor accepted after September 20, 2006, will be published only in the online version of the journal. Online-only letters will still be listed in the table of contents of the print version and will be assigned an "E" page number, but they should be cited by use of their DOI (digital object identifier) rather than a page number (e.g., 10.2337/dc07-XXXX).

Letters do not have abstracts and should not exceed 500 words, including the references. The inclusion of tables or figures in letters is discouraged. As with all submissions, letters should be double-spaced and include a title page with the authors' full names, degrees, and affiliations and the corresponding author's contact information. For Comment and Response letters, the article on which the letter comments, or responds to, should be included as reference 1 in the reference list. The editor reserves the right to ask authors of the cited article to respond.

Manuscript Submission Tip: To bypass the "Abstract" field when submitting a Letter to the Editor, type "None" in the "Abstract" field. For more information on uploading your manuscript, see the Submitting a Manuscript section.

Acknowledgments

The acknowledgments should go after the main text and before the reference list. Acknowledgments should contain brief statements of assistance, financial support, and prior publication of the study in abstract form, where applicable.

References

The reference list should go at the end of the document, after the main text and acknowledgments (if applicable) and before the tables. References should be numbered in the order that they are cited in the text.

Reference numbers in the text should be in normal type and in parentheses [e.g., "In the study by Norton et al. (23)..."]. Please do not use the footnote/endnote functions found in some word processing programs.

For examples of how to style each reference in the reference list, see "References" in the Manuscript Style section.

Tables

Tables should be double spaced on separate pages and included at the end of the text document, with the table number and title indicated. Tables should be created using Word and the "Insert Table" command; please do not use tabs and/or spaces to create tables, columns, or rows. Use Arial or Times New Roman Font, no smaller than 10pt. Tables with internal divisions (Tables 1A and B) should be submitted as individual tables, i.e., Tables 1 and 2. Symbols for units should be confined to column headings. Abbreviations should be kept to a minimum and defined in the table legend. For footnotes, use the following symbols consecutively, left to right, top to bottom of table: *, †, ‡, §, ||, ¶, #, **, ††, etc.

If tables are taken from other sources, the author must be able to provide written permission for reproduction obtained from the original publisher and author.

Figures

Diabetes Care uses digital publishing methods throughout the journal production process. If your article is accepted, it will be published both in the printed journal and online. The following sections provide information on how to format your figures to ensure the best possible reproduction of your images.

Size. Figures should be produced at the size they are to appear in the printed journal. Please make sure your figures will fit in one, two, or three columns in width. Multi-paneled figures should be assembled in a layout that leaves the least amount of blank space.

1	column	=	13	picas	wide,	2.2	in,	5.6	cm
2	columns	=	28	picas	wide,	4.6	in,	11.7	cm
3	columns	=	41	picas		6.8	in,	17.3	cm

Font. At 100% size, fonts should be 8-10 points and used consistently throughout all figures.

Text. Information on the axes should be succinct, using abbreviations where possible, and the label on the y-axis should read vertically, not horizontally. Key information should be placed in any available white space **within** the figure; if space is not available, the information should be placed in the legend. In general, figures with multiple parts should be marked A, B, C, etc., with a description of each panel included in the legend rather than on the figure.

Line and bar graphs. Lines in graphs should be bold enough to be easily read after reduction, as should all symbols used in the figure. Data points are best marked with the following symbols, again assuring that they will be readily distinguishable after reduction: ○ ● □ ■ △ ▲. In the figure legend, please use words rather than the symbols; e.g., "black circles = group 1; white squares = group 2; black bars = blood glucose; white bars = C-peptide." Bars should be black or white only, unless more than two datasets are being presented; additional bars should be drawn with clear bold hatch marks or stripes, **not** shades of gray.

Line or bar graphs or flow charts with text should be created in black and white, **not** shades of gray, which are difficult to reproduce in even tones.

Color figures. Color figures incur an additional charge of \$630 per color figure. (Note: Charges apply to each figure as a whole, not by the part, i.e., A, B, C, etc.). Color figures should not be submitted for reproduction in black and white. If you submit figures in color but request to have them reproduced in black and white or submit charts or graphs with gray backgrounds or bars, you will be asked to send new figures and the publication of your paper may be delayed. If you choose not to submit new figures, the publisher cannot be held responsible for the print quality of the images.

Reproductions. If materials (e.g., figures and/or tables) are taken from other sources, the author must be able to provide written permission for reproduction obtained from the original publisher and author. In addition, the source should be cited at the end of the figure legend.

Figure legends. Figure legends should be clearly numbered and included at the very end of your main text document and should not be included on the separate figure/image files. Please use words to describe symbols used in the figure; e.g., "black circles = group 1; white squares = group 2; black bars = blood glucose; white bars = C-peptide."

Formatting digital files for print reproduction. Computer screens, laser printers, and offset presses are significantly different devices. The ability to print your graphics well on a desktop laser printer does not mean the image can be printed successfully, or at all, on an offset press. Please read these basic guidelines to help you prepare image files that will provide high-quality reproductions, both in print and online. For additional information on how to properly prepare digital art, visit the Cadmus KnowledgeWorks Digital Art Web site.

As noted in the guidelines, it is strongly recommended that authors check the acceptability of digital images for production by running the files through Rapid Inspector, a free tool provided at <http://rapidinspector.cadmus.com/RapidInspector/z99/index.jsp>.

Manuscript Submission Tip: Figures are to be uploaded individually as separate files and should not be included in the main text document. Please see further detailed instructions in the Submitting a Manuscript section.

MANUSCRIPT STYLE

Terminology and Style

Articles should be written in clear, concise English following the recommendations for scientific writing found in *Scientific Style and Format*, the Council of Biology Editors (CBE) style manual (6th ed., 1994, Bethesda, MD, Council of Biology Editors). All accepted manuscripts will be edited according to the CBE style manual and *The Chicago Manual of Style* (15th ed., 2003, Chicago, IL, The University of Chicago Press) by ADA professional publications staff. The authors are responsible for all statements made in their articles or editorials, including any editing changes made by staff.

The designations *type 1 diabetes* and *type 2 diabetes* should be used when referring to the two major forms of diabetes. Abbreviations for diabetes, such as *T2D* for *type 2 diabetes*, should not be used. The term *diabetic* should not be used as a noun.

Abbreviations

Abbreviations should be used only when necessary, e.g., for long chemical names (HEPES), procedures (ELISA), or terms used throughout the article. See the list of abbreviations that need not be defined; all others must be defined at first use. Abbreviate units of measure only when used with numbers. Abbreviations may be used in tables and figures. The CBE style manual contains lists of standard scientific abbreviations.

Units

Clinical laboratory values should be in Système International (SI) form (see SI table in each issue). Kilocalories should be used rather than kilojoules. Glycated hemoglobin should be expressed as percentage of total and as standard deviation from mean control levels.

Materials

Authors should provide the name and location (city and state/country) of the source for specified chemicals and other materials only if alternate sources are considered unsatisfactory.

References

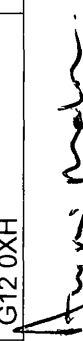
References should be listed according to the following examples and should be numbered in the order that they are cited in the text. All authors must be listed and inclusive page numbers provided. Journal titles should be abbreviated as in the National Library of Medicine's List of Journals Indexed for Medline; for unlisted journals, complete journal titles should be provided. Material that is in press may be cited, but copies of such material may be requested. Authors are responsible for the accuracy of the references.

Appendix 4.2: Greater Glasgow NHS Trust Ethics Committee Letter of Approval -

NHS Greater Glasgow Primary Care Division (Community & Mental Health)

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	05/S0701/71	Issue number:	1	Date of issue:	07 July 2005
Chief Investigator:	Ms Kirsten. D. Kernohan				
Full title of study:	Similarity of adolescent and maternal illness representations of Type 1 diabetes: Its relationship to self-management, self-efficacy, well-being and adherence to treatment in the adolescent with diabetes.				
<p><i>This study was given a favourable ethical opinion by NHS Greater Glasgow Primary Care Division (Community & Mental Health) on 30 June 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.</i></p>					
<i>Principal Investigator</i>	<i>Post</i>	<i>Research site</i>	<i>Site assessor</i>	<i>Date of favourable opinion for this site</i>	<i>Notes ⁽¹⁾</i>
Ms Kirsten. D. Kernohan	Trainee Clinical Psychologist	Mr Brian Rae NHS Greater Glasgow NHS Greater Glasgow Research & Development Directorate Garthavel Royal Hospital 1055 Great Western Road, Glasgow G12 0XH	NHS Greater Glasgow Primary Care Division (Community & Mental Health)	07/07/2005	
<p>Approved by the Chair on behalf of the REC: </p>					

Copy of Questionnaire	well being questionnaire	(None Specified)
Copy of Questionnaire	summary of diabetes self-care activities	(None Specified)
Copy of Questionnaire	your views about your son or daughter's diabetes	(None Specified)
Copy of Questionnaire	your views about your diabetes	(None Specified)
Letters of Invitation to Participants	one	12 May 2005
Participant Information Sheet	one-adolescent group	(None Specified)
Participant Information Sheet	one - maternal group	(None Specified)
Participant Consent Form	maternal group	12 May 2005
Participant Consent Form	one - adolescent	(None Specified)
Response to Request for Further Information		21 June 2005
Other	one	17 March 2005

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor [that the study has a favourable ethical opinion.

Statement of compliance

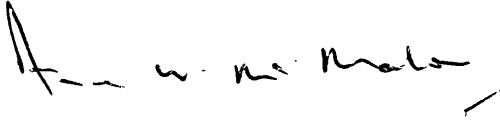
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/S0701/71

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely



Mrs Anne McMahon
Ethics Committee Manager on behalf of
Dr Paul Fleming (Chairman)

09/06/2005/41

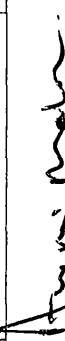
Enclosures:

Attendance at Sub-Committee of the REC meeting on 30 June 2005
Standard approval conditions
Site approval form (SF1)

NHS Greater Glasgow Primary Care Division (Community & Mental Health)

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	05/S0701/71	Issue number:	1	Date of issue:	07 July 2005
Chief Investigator:	Ms Kirsten. D. Kernohan				
Full title of study:	Similarity of adolescent and maternal illness representations of Type 1 diabetes: Its relationship to self-management, self-efficacy, well-being and adherence to treatment in the adolescent with diabetes.				
<p><i>This study was given a favourable ethical opinion by NHS Greater Glasgow Primary Care Division (Community & Mental Health) on 30 June 2005. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.</i></p>					
Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes ⁽¹⁾
Ms Kirsten. D. Kernohan	Trainee Clinical Psychologist	Mr Brian Rae NHS Greater Glasgow NHS Greater Glasgow Research & Development Directorate Garthavel Royal Hospital 1055 Great Western Road, Glasgow G12 0XH	NHS Greater Glasgow Primary Care Division (Community & Mental Health)	07/07/2005	
<p>Approved by the Chair on behalf of the REC:</p> 					

Appendix 4.3: Research and Development Letter of Approval

Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 3600
www.nhs.org.uk

Ms Kirsten Kernohan
Trainee Clinical Psychologist
Section of Psychological Medicine
Division of Community Sciences
Gartnavel Royal Hospital
1055 Great Western Road, Glasgow
G12 0XH

Date
Your Ref
Our Ref BR/AW/approve

Direct Line 0141 211 3661
Fax 0141 211 3814
Email [annette.watt@](mailto:annette.watt@gartnavel.gla.ac.uk)
 gartnavel.gla.ac.uk

Dear Ms Kernohan

Project Reference Number: 05CP08

**Project Title: Similarity of adolescent and maternal illness representations of Type 1
 diabetes: Its relationship to self-management, self-efficacy, well-being and
 adherence to treatment in the adolescent with diabetes**

Thank you for completing the Research & Development (R&D) Management Approval Application for the above study. I am pleased to inform you that R&D management approval has been granted by Greater Glasgow Primary Care Division subject to the following requirements:

- You should notify me of any changes to the original submission and send regular, brief, interim reports including recruitment numbers where applicable.
- Your research must be conducted in accordance with the National Research Governance standards. (see CSO website: www.show.scot.nhs.uk/cso)
Local Research Governance monitoring requirements are presently being developed. This may involve audit of your research at some time in the future.
- You must comply with any regulations regarding data handling (Data Protection Act).
- Brief details of your study will be entered on the National Research Register (NRR). You will be notified prior to the next submission date and asked to check the details being submitted.
- A final report, with an abstract which can be disseminated widely within the NHS, should be submitted when the project has been completed.

Do not hesitate to contact the R & D office if you need any assistance.

Thank you again for your co-operation.

Yours sincerely



Brian Rae
Research Manager



Yorkhill Division

Research & Development Office

Dalnair Street
Glasgow
G3 8SJ

Tel: (0141) 201 0005

E-mail: alison.wood@yorkhill.scot.nhs.uk

Ms Kirsten D Kernohan
Trainee Clinical Psychologist
University of Glasgow
Section of Psychological Medicine
Gartnavel Royal Hospital
Glasgow G12 0XH

27th July 2005

Yorkhill R&D Management Approval

Dear Ms. Kernohan,

Re: Project ID 05/DI/01 - Community Child Health: Similarity of Adolescent and maternal illness representations of Type I diabetes: Its relationship to self-management, self-efficacy, well-being and adherence to treatment in the adolescent with diabetes (Ethics Ref: M26/05:05/S0708/41)

I am pleased to inform you that your project has been approved by the Yorkhill Division R&D department. This letter ensures that you and the researchers working with you, who hold substantive or honorary contracts, are indemnified by the NHS under the CNORIS scheme. This means you can now proceed with your project at Yorkhill, as we have written confirmation of ethics approval for the study.

Amendments – The R&D office needs to be kept informed of any changes to the project for example regarding patient recruitment, funding, personnel changes or your project status. If changes are made to the protocol they will need to be considered by the ethics committee.

Should you have any queries please contact the R&D office quoting the Project ID number. Please let me know if the R&D office help in any way with the study. May I wish you every success with your research.

With very best wishes,
Yours sincerely,

A handwritten signature in black ink, appearing to read 'Alison Wood'.

Dr. Alison Wood
Research & Development Manager

Appendix 4.4: Visual Analogue Scale – Self-Efficacy

17.03.05 Version 1.0

Participant no. **Date:**

The following questions ask you about how confident you feel carrying out your treatment of your diabetes.

Please make a mark on the line to show how much you agree with each of the following statements.

1. I feel confident doing my blood glucose checks on my own with no help from others.

Not at all

All the time

2. I feel confident doing my insulin injections on my own with no help from others.

Not at all

All the time

3. I feel confident about knowing which foods I should eat and deciding what to eat without the help of others

Not at all

All the time

4. I feel confident about knowing how much exercise I should do and deciding to exercise without help from others

Not at all

All the time

Thank-you for answering these questions.

